

**PSYCHOMETRIC PROPERTIES OF A NEW SCALE FOR
MEASURING ANXIETY IN PEOPLE WITH A LEARNING
DISABILITY: THE GLASGOW ANXIETY SCALE FOR
PEOPLE WITH A LEARNING DISABILITY (GAS-LD)
AND
RESEARCH PORTFOLIO**

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**Submitted in part fulfilment of the degree requirements of the Doctorate in Clinical
Psychology, within the Faculty of Medicine, University of Glasgow**

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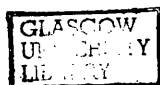
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Literature Review

THE ASSESSMENT OF ANXIETY IN PEOPLE WITH A LEARNING DISABILITY: A REVIEW HIGHLIGHTING THE NEED FOR VALIDATED SCALES.

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Abstract

There has been relatively limited research on the mental health of people with a learning disability, in spite of the high prevalence of disorder in this population. Anxiety disorders are among the most common psychological difficulties, and comprise a considerable proportion of research effort in the general adult field. However there is a dearth of research involving people with a learning disability. Consequently models of anxiety are based on the general adult population and there has been little consideration of the way in which anxiety in people with a learning disability should be conceptualised. One reason for this, may be the difficulty in developing relevant assessment tools due to communication problems and lack of procedural standardisation in a relatively heterogeneous population. However the recent development of a DSM-IV based psychiatric interview represents substantial progress in this area. In this review the need for the development of self-report measures of anxiety is considered in some depth. Such measures are widely available in adult mental health and are useful for symptom screening, outcome measurement and as an aid to diagnosis. The development of a reliable and valid scale for use with people with a learning disability is long overdue.

There has been a growing awareness of the need to research the area of mental health problems in people with a learning disability, to improve our knowledge of the aetiology, presentation, occurrence and treatment options. In the last fifteen years there has been increased interest in this area which is long overdue considering the prevalence and effects of mental illness in this group. Sovner and Hurley (1983) asserted that the full range of mental health problems seen in the general population are also seen in the learning disabled population but that the prevalence rate is four to five times that of the general population (Eaton & Menolascino, 1982), though these figures may be inaccurate due to difficulties in identifying anxiety in this population. Fraser et al (1986) reported that anxiety was one of the most frequently diagnosed psychiatric symptoms in people with a learning disability. Pathological levels of anxiety were reported in 6% of individuals with a learning disability who were residents in a mental handicap hospital, of whom a third needed inpatient care (Ballinger et al, 1991). Bouras and Drummond (1992) found similar levels of anxiety disorder (6.6%) in groups of learning disabled individuals living in the community compared with approximately 3% in the general population (Marks & Lader, 1973). Some of the estimates are from studies which used clinical evaluation of psychopathology by experienced clinicians rather than assessment tools, which although not standardised is probably more valid (e.g. Szymanski, 1977). After studying a Swedish population, Gostason (1985) suggested that “mildly retarded persons are more emotionally labile, with greater tendency to nervous breakdown under stress and/or a mental morbidity of greater extent or severity than persons of higher intelligence” (pp.102). There are a number of other risk factors for mental illness which are more frequently present for people with a learning disability including genetic abnormalities, adverse drug effects, limited life experience, low self-esteem, little control over their environment and limited social support networks (Moss et al, 98) which would support the estimated high prevalence.

In Bednar & Kaul's (1994) review of research in psychotherapy they describe three key aspects to researching a 'young area'. These are identifying central conceptual factors; classifying the central phenomena of the discipline; and developing measurement methods for quantifying these basic concepts. In spite of the importance of developing measurement materials, the high estimated prevalence of mental health problems and the resulting impact on the individual's quality of life, there has been great difficulty in developing a satisfactory

means of identifying and diagnosing mental illness, leaving many people without appropriate treatment or service provision.

Historical conceptualisation of anxiety

Insert Table 1 here

There have been many different theoretical models of anxiety including those developed from learning theory (e.g. Mowrer, 1939), cognitive theory (e.g. Beck et al, 1985), psychodynamic theory (e.g. Freud, 1948, 1950) and biological theory (e.g. Klein, 1987). Table 1 describes some of the key developments in the conceptualisation of anxiety, though there has been a considerable amount of important research which is not included. The basis of current conceptualisations lies with the three systems model of anxiety (Lang, 1968; Rachman, 1976) where thoughts (cognitive anxiety or worry), emotions and behaviour (e.g. fear and avoidance) and physiology (somatic anxiety) are thought to interact in order to determine the level of anxiety experienced in a given situation. The cognitive aspect of this model was the focus of Beck et als’ (1985) cognitive model of anxiety in which the biased interpretation of a situation as threatening to the individual, is central to the experience of anxiety. Beck & Clark (1997) have broken down the interpretation of stimuli to develop a three-stage schema-based information processing model involving the registration of a threat and activation of a ‘primal threat mode’ followed by more complex processing. In addition to the processing of stimuli, it is important to consider whether this style of interpretation reflects State Anxiety i.e. transitory, or Trait Anxiety i.e. “a relatively stable individual difference in anxiety proneness” Pp3 (Spielberger et al, 1970). However, although these phenomena have been differentiated, Spielberger et al suggest that people who are high in Trait anxiety will exhibit more State anxiety as they are more reactive to potentially anxiety provoking situations.

In addition to conceptualising the mechanism by which incoming information is processed, the role of different components of anxiety in the pattern of symptoms observed has been considered, in particular the concept of worry. Borkovec et al (1983) defined worry as “a chain of thoughts and images, negatively affect-laden and relatively uncontrollable. The

worry process represents an attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes” (Pp10). Borkovec and Inz (1990) assert that worry (or cognitive anxiety), rather than somatic anxiety correlates most strongly with other aspects of anxious behaviour. Wells (1995) introduced the concept of “meta-worry” or worrying about worrying, which has been shown to discriminate between the worry of people with and without generalised anxiety disorder.

Conceptualisation of anxiety in people with a learning disability

In spite of these developments in the conceptualisation of anxiety in people of average intellectual ability, there has been little research to determine whether these models are equally applicable to learning disabled people especially to those with moderate or profound disability and/or no verbal communication. A key factor is whether people with a learning disability have the abstract thinking and verbal skills to have the same cognitive processes as are apparent in the general population. It may be that some stages of processing incoming information remain the same, while other aspects are different. For example in Beck & Clark’s (1997) Three-stage model discussed earlier, they suggest that the first two stages involve “more primitive and immediate cognitive/ affective/ behavioural /physiological patterns aimed at meeting evolutionary derived objectives such as survival (and) safety...”(pp52). The third stage in comparison involves “more reflective consideration of the current context and their coping resources” (pp53). This stage requires a higher level of processing so it is probable that any cognitive impairment would have a greater impact here than on the first two stages. It is also at this stage that Beck & Clark (1997) hypothesise ‘worrying’ takes place. Worry is considered to primarily involve thoughts rather than imagery (Borkovec & Inz, 1990) suggesting worry is verbally encoded. If this is the case, can people without verbal skills worry (Mathews, 1990)?

Many people with a learning disability have difficulty expressing their ideas verbally but this does not mean they do not have thoughts. However if someone’s language and verbal comprehension is very limited, it is possible that, when they experience anxiety, imagery and somatic sensations may play a greater role than thoughts. James (1999) has proposed a conceptualisation of anxiety in people with dementia. While this is clearly a different population, he suggests the use of features from the cognitive model, which are ‘filtered through’ cognitive abilities taking account of variations in peoples’ cognitive abilities.

Information processing would be affected by the degree of cognitive impairment, resulting in some ‘abnormal interpretations’. He stresses the utility of this model in helping both the therapist and carers understand the individual’s experience.

As there has been no evaluation of cognitive models of anxiety in people with a learning disability, it is impossible to say which aspects of anxiety models are applicable. However it would seem prudent, in designing a scale, to base our understanding of anxiety on anxiety models which place a greater emphasis on non-verbal processes including the role of learning, physiology and emotional experience rather than concentrate solely on the, potentially different, cognitive aspects. The Three systems model of anxiety (Lang, 1968; Rachman, 1976), in which thoughts, emotions, behaviour and physiology are thought to interact in order to determine the level of anxiety experienced in a given situation, is the most relevant. The Three systems model allows for variation in the relative involvement of the different components, which with this client group, accommodates a reduction in the role of cognitions in people with reduced verbal ability and reasoning skills. This allows us to consider how people with a learning disability might experience and express their anxiety and understand how this experience may vary with level of intellectual and verbal ability. Thus in people with a severe learning disability, emotions such as fear, along with the physiological symptoms may constitute anxiety. In turn in this client group, rather than expressing distress verbally, behavioural expression is more likely for example by withdrawal or self-soothing behaviours such as rocking.

The term “anxiety” covers a range of forms (e.g. cognitive, somatic), diagnoses (e.g. Generalised Anxiety Disorder, Panic Disorder) and duration (transitory, stable). In the development of a questionnaire different aspects of anxiety will be evaluated. It is important to be aware of these different components that interact to produce a variety of experiences of anxiety. In order to have a conceptually pure questionnaire these different components should be identified and evaluated separately. However, this presumes that the conceptualisation is valid, and when investigating a concept with a different population, this cannot be assumed. One way of attempting to minimise this difficulty is to ask the relevant population themselves about their experience of anxiety. Further research in this area may clarify the interaction between cognitions, emotions and physiological sensations in this

population and add to our understanding of the theoretical underpinnings of anxiety in people with a learning disability.

Approaches to the assessment of anxiety in people with a learning disability

A variety of approaches to developing assessment tools have been taken including adapting self-report measures from the general adult population (e.g. Adapted Zung Self-rating Anxiety Scale, Lindsay and Michie, 1988); adapting structured interviews (e.g. Clinical Interview Schedule, Ballinger et al, 1975); developing semi-structured interviews for people with a learning disability (Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD), Moss et al, 1994); developing self-report measures (Psychopathology Instrument for Mentally Retarded Adults (PIMRA), Matson et al, 1984) and developing assessments for use with informants (e.g. PAS-ADD checklist; Moss, 1998). These measures serve different roles in the detection, diagnosis, and evaluation of mental health problems in people with a learning disability, with associated advantages and disadvantages.

Adapted Zung Self-rating Anxiety Scale

This scale was adapted from Zung's 1971 scale for measuring anxiety in the general adult population. However Zung's original scale had a number of shortcomings including:- that it was developed using a group of participants only 22 of whom had a diagnosis of anxiety; the participants were primarily inpatients, reducing the generalisability of the scale to other populations; it was based on diagnostic criteria in DSM-II which have subsequently been updated; the validity of individual items has not been assessed and Beck et al (1988) found that some items correlated more closely to the Beck Depression Inventory than the Beck Anxiety Inventory.

In addition to the limitations of the original scale, Lindsay and Michie's (1988) process of adaptation focused on changing the wording and response options of the scale. They did not compare the reliability and validity of using their adaptation with other forms of assessment of anxiety with people with a learning disability. It is possible therefore that although the majority of the participants could understand the language used, they could not understand the underlying concepts. Their subject pool only consisted of 29 adults who were not necessarily anxious. At prevalence rates of 6-7% (Ballinger et al, 1991; Bouras and

Drummond, 1992), it would be predicted that only two people out of the sample would have a diagnosis of anxiety and so it has not been established whether the questionnaire differentiates between individuals who have experienced some anxiety symptoms (i.e. most people) and people who are experiencing a clinically significant level of anxiety. They did evaluate different response options however and found the Yes/No option more reliable than the four-response option. Adapting an assessment measure from the general adult literature saves time in development while using more appropriate language and response options. However any problems with the original scale are reproduced and no account is taken of differences in the presentation of anxiety in different populations.

Clinical Interview Schedule

Ballinger et al (1975) adapted the Clinical Interview Schedule (Goldberg et al, 1970) for use with people with a learning disability. The initial scale was designed for use with a community sample but was evaluated with an inpatient group as was the adaptation. There were some concepts that the authors reported were rarely understood by the participants such as depersonalisation, obsessions and compulsions along with the time scale of the symptoms but they felt overall the interview was of value with this population. There are two main limitations of this type of assessment however. The first is the time taken to carry out the assessment, which while necessary for initial assessment, is often impractical when repeated administration is required. This in effect limits the schedule's use to diagnosis, as it is too cumbersome to use to evaluate the effectiveness of symptom management. Secondly the interview was designed to be administered by a trained psychiatrist. Ballinger et al (1975) found that the clinical psychologist's ratings correlated well with those of psychiatrists but clearly the format requires a experienced mental health practitioner which again limits its use.

Psychopathology Instrument for Mentally Retarded Adults (PIMRA)

The PIMRA (Senatore et al, 1985) was the first assessment tool developed specifically for assessing mental health problems in this population. It consists of 56 items based on DSM-III classification and draws on information from both the patient and a carer. However there are a number of problems with it. The scale was validated against depression scales, rather than more comprehensive measures which would have provided some validation of the anxiety items. Only one of the 110 participants the scale was developed with, had a

diagnosis of anxiety so information about the anxiety components validity would not be available from the clinical data. In addition, in a study to evaluate the psychometric properties of the PIMRA with a British, rather than American, population, Sturmey and Ley (1990) found “barely acceptable internal consistencies”, and were critical of both the scoring system and the use of the affective, somatoform and psychosis dimensions which they found to be problematic.

Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD, Moss et al, 1994,1998)

In the development of the PAS-ADD, the authors have attempted to address many of the problems of previous measures and have made substantial progress. The PAS-ADD consists of three components, the checklist, the mini PAS-ADD and the diagnostic interview. Each component has questions relating to a range of mental health problems including anxiety, depression, psychosis and developmental disorders, requiring different levels of detail about the presenting problem. The checklist is brief and to be used as a screening instrument with carers to identify people who need a more thorough psychiatric assessment. The Mini-PAS-ADD aims to provide a more detailed initial assessment and can only be administered by learning disability or mental health professionals, again with carers rather than the individual concerned. The PAS-ADD diagnostic interview is used by professionals, trained in its use, to diagnose mental health problems through interviews with both the identified patient and a carer. These tools have a number of strengths. They were designed specifically for the learning disabled client group by experienced clinicians and thoroughly evaluated with a clinical population. The format of the different components allows the assessment of people with a wide range of learning disability and for a range of purposes. However some of the PAS-ADD’s strengths can also be problematic for example the diagnostic interview is very comprehensive but as a result is time consuming so is of use for diagnosis but less practical for treatment evaluation. This is problematic when measuring a particular mental health problem, in this case anxiety, where repeated assessment of other areas is not necessary, especially with clients who may have a relatively short attention span. Although the mini-PAS-ADD and the checklist are much quicker they rely on carers for information rather than the individual and so are less reliable. They also cover a cross section of mental health problems so the information about anxiety for example is very limited. Therefore in

spite of there being significant improvements in the available measures, there are still gaps for measuring some aspects of anxiety.

Features which need to be considered in the development of a valid scale

In discussing the measures available for use with learning disabled people, some difficulties have been highlighted including problems with diagnosis, differences in symptoms presentation, cognitive ability and communication factors.

Diagnosis

Diagnosis can be problematic due to difficulties in categorisation. In all areas of mental health, the same symptoms can be associated with different disorders, depending on the combination of other symptoms. However with people with a learning disability, there may be less information available about other symptoms making diagnosis difficult. In addition, many people with a learning disability have other problems such as brain damage or epilepsy, which may complicate the presentation especially when on medication. As in any diagnosis, emphasis is placed on change in behaviour or mood, and so carers need to be aware of the significance of changes. Patel et al (1993) found that by using the PAS-ADD, they were able to identify people who had Generalised Anxiety Disorder and Agoraphobia who had previously gone unrecognised. Bouras & Drummond (1992) found that in people with a mild learning disability, symptoms were the same as those seen in the general population, however in people with moderate and severe learning disability, the symptoms were highly individualistic. Any diagnosis therefore needs to be able to accommodate variation in symptom presentation without being so all encompassing that the diagnosis becomes meaningless. The format of the PAS-ADD Checklist (Moss et al, 1998) attempts to address this by developing the scale specifically for and with people with a learning disability and having a threshold of symptoms above which a more thorough assessment should be carried out.

Differences in symptomatology

Lindsay et al (1994) showed that with a group of people with a mild or moderate learning disability, when a variety of measures were used, the participants' results "reveal an impressive amount of convergent validity in the subjects' emotional systems". However research carried out considering depression in people with a learning disability found that in

people with a moderate or severe learning disability, instead of the standard diagnostic criteria “there was a move towards ‘behavioural depressive equivalents’ such as aggression, screaming and self-injurious behaviour” (Marston et al, 1997 pp.476). As the self-report scales have been adapted from the general adult literature, and not developed specifically for this client group, they do not take account of ‘behavioural equivalents’ or changes in the centrality of particular symptoms for diagnosis.

Communication factors

Communication factors can be particularly problematic when attempting to determine a psychiatric diagnosis, especially with non-verbal people (Moss et al, 1997). The individual may find it difficult to explain or even understand what s/he is feeling or experiencing, and health professionals struggle to interpret the communication which may be delivered verbally, through affect or through behaviour. It can be difficult to estimate the level of psychological stress felt by people who have no verbal communication. Chaney (1996) addressed this by recording the vital signs, temperatures and facial expressions of people with profound learning disability in reaction to pleasant and unpleasant stimuli. He found that his participants differentiated between the different stimuli and showed anxious responding when an unfamiliar person approached them or they were stared at. Different strategies have been used to overcome communication difficulties including asking relatives and carers about the individual’s behaviour and affect, and observing behaviour.

The language used in interviews or questionnaires to describe symptoms is crucial as many words convey complex, abstract concepts such as anxiety, which some people with a learning disability will not understand. The use of colloquial language can aid understanding, but limit the generalisability of the measurement. However Lindsay & Michie (1988) point out that the generalisability is irrelevant if the scale does not measure valid constructs. Some words may have a very specific academic meaning while in general usage be used to convey a much broader idea. These words need to be used with caution, with the intended meaning clarified.

Other considerations include the time scale of the measurement, as people with a learning disability may have a poor concept of time and struggle to give accurate information about the frequency and duration of symptoms. Moss et al (1994,1997,1998) used a ‘time anchor’

where they asked the learning disabled individual to think of a significant recent event and describe their feeling since that point. Because the person is asked to suggest an event themselves it clarifies that this is a time point that they remember. Efforts need to be made to use short questions with only a simple response format which should be repeated for each question. Lindsay & Michie (1988) used a yes/no dichotomy but this creates difficulties as many symptoms, particularly of anxiety, are experienced by most people at some time so asking if they have experienced the symptom could be meaningless. The whole assessment should be as brief as possible. Information can be supplemented by asking informants but they may not always be aware of symptoms experienced by the individual.

Conclusion

This paper draws attention to the measurements currently available for assessing anxiety in people with a learning disability, the problems with them as well as the gaps in their applicability. It also highlights some of general difficulties in the development of assessment tools for this population including the lack of a clear, conceptual understanding of anxiety in this group, the problems surrounding diagnosis and differences in symptom manifestation, and communication factors.

This study aims to develop a short, self-report measure of anxiety for people with a learning disability which can be used to screen for anxiety and subsequently, in treatment and research, to evaluate change. It will be based on the Three systems model of anxiety (Rachman, 1976) as this model is sufficiently flexible to account for the experience of anxiety in people with a range of cognitive abilities without excluding potentially significant aspects of anxiety. It is hoped that having a valid yet quick and reliable assessment measure will allow more extensive research to be carried out into different aspects of anxiety in people with a learning disability, especially its identification and treatment. This should also lead to a clearer theoretical understanding of anxiety in people with a learning disability.

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Table 1. Significant conceptualisations of and development of measures of anxiety.

<u>Date</u>	<u>Principal Authors</u>	<u>Theoretical Basis</u>	<u>Publication of Scales</u>
1939	Mowrer	Two-Stage theory of Fear and Avoidance	
1948, 50	Freud	Psychodynamic theory of anxiety	
1959	Hamilton	No explicit model but physiological emphasis	Hamilton Anxiety Scale
1966	Lazarus	Threat Appraisal	
1968	Lang	Preliminary development of Three Systems Model of Anxiety	
1970	Spielberger et al	State versus Trait Anxiety	State-Trait Anxiety Inventory
1971	Zung	No explicit model but physiological emphasis	Zung Anxiety Status Inventory
1976	Rachman	Further development of Three Systems Model of Anxiety	
1976	Beck	Cognitive Model	
1983	Borkovec et al	Concept of Worry	
1985	Beck	Cognitive Model of Anxiety	
1987	Klein	Biological theory of Anxiety	
1988	Beck		Beck Anxiety Inventory
1990	Meyer et al	Focus on worry	Penn State Worry Questionnaire
1994	Tallis & Eysenck	New model of worry with alarm, prompt and preparation function	
1995	Wells	Concept of Meta-worry - worrying about worrying	
1997	Beck & Clark	Information Processing Model automatic vs strategic processes	

GREATER GLASGOW COMMUNITY AND MENTAL HEALTH SERVICES NHS TRUST

SUBMISSION OF RESEARCH PROTOCOLS TO THE RESEARCH ETHICS COMMITTEE

All research protocols for consideration by the Research Ethics Committee of Greater Glasgow Community and Mental Health Services NHS Trust must be submitted on the standard application form, a copy of which is enclosed. Your attention is drawn to the guidance notes to researchers, and it is suggested that you read these prior to completing your application.

The application must be completed even when a separate protocol (for example, prepared by a pharmaceutical company) exists.

If you wish advice on completing your application, or any aspect of the study you are proposing to undertake please contact Mrs Anne McMahon, Medical Director's Office, Trust Headquarters, Gartnavel Royal Hospital. Tel: 0141-211-3824.

GREATER GLASGOW COMMUNITY AND MENTAL HEALTH SERVICES NHS TRUST

APPLICATION FORM FOR ETHICAL APPROVAL

NOTES: This application form must be *typed*, not hand written.

All questions must be answered: it is not an acceptable answer to put see '*separate protocol*'; '*not applicable*' is a satisfactory answer where appropriate.

Where a separate protocol exists, this should be submitted in addition to the application form.

1. Name and status of proposer:

Jane Mindham
Trainee Clinical Psychologist

Supervisor: Professor Colin Espie
Department of Psychological Medicine

2. Address for correspondence:

Jane Mindham
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

3. Employing authority:

Greater Glasgow Community and Mental Health Services NHS Trust

4. In which hospital(s) or other location will the study be undertaken:

Resource centres for people with a learning disability in the Greater Glasgow area.

5. Title of project:

Psychometric Properties of a New Scale Measuring Anxiety in People with a Learning Disability: The Glasgow Anxiety Scale for People with a Learning Disability (GAS-LD)

6. Has the proposed research been approved by any other committee on ethics? (Give details): No

7. Has the proposed, or similar, research been carried out in any other centre? (Give details)

No

8. Please give a summary of the project, including the question to be answered, the procedures to be used, the measurements to be made and how the data will be analysed (please see question 12 for recording details of how consent is to be obtained):

This study is concerned with developing a measure of anxiety symptoms in people with a learning disability. In spite of the large number of scales available for measuring anxiety in the general adult population, there are only limited measures for use with a learning disabled population. This is primarily due to communication difficulties and cognitive impairments. These factors mean a standardised and sensitive measure would be particularly useful.

Items used in the development of the scale will be collated from information gathered at a workshop about anxiety for people with a learning disability, clinicians working in the field, and from other relevant scales and literature.

The scale will be validated with three groups of participants initially:- people with a learning disability and anxiety; people with a learning disability but no anxiety and anxious non-learning disabled people. Participants will be screened using the PAS-ADD structured interview and a draft of the questionnaire will be administered. Statistical analysis will then be used to determine which items to include in the final scale. The non-learning disabled group will also be given the Beck Anxiety Inventory (Beck et al, 1988) for comparison of results. An additional component of the study is an attempt to measure physiological concomitants of anxiety in people with a learning disability. A subgroup of participants will complete the questions and look at pictures during which time their pulse rate will be monitored. A baseline period before and afterwards, while the pulse rate is being measured, will allow changes in pulse rate, due to the questions or pictures, to be identified.

Aims

This study has three aims:

1. To develop a self-report anxiety questionnaire for people with a learning disability.
2. To validate this questionnaire on different groups of people with and without a learning disability.
3. To validate this questionnaire using clinicians reports, existing measures including a structured interview (PAS-ADD), and physiological measures of anxiety.

Hypotheses

1. Some individuals with a learning disability will experience anxiety.
2. It is possible to develop a self-report questionnaire to measure this anxiety which will correlate with clinicians reports, other scales and physiological measures of anxiety.

The data will be analysed using a variety of statistical tools as described in question 14.

9. Please state whether there are any expected benefits to patient care and, if so, summarise:

The implications of developing a scale would be the identification of anxiety symptoms for clinical intervention and research purposes and for the evaluation of treatment methods to further the understanding and treatment of anxiety. Psychological treatment for anxiety has been used successfully with people with a learning disability (e.g. Lindsay & Morrison, 1996) and so identifying a population who are particularly vulnerable to anxiety could have beneficial results both in terms of targeting limited resources and helping people who may have difficulty expressing their needs clearly themselves.

10. Please state the likely duration (a) of the project itself and (b) for individual patients:

- (a) - Recruitment of participants and a pilot study will occur between July and August 1998.
 - Any modifications required to be made and the majority of the data collection will occur between September 1998 and February 1999.
 - Data analysis and writing up the study will take place between March and June 1999.
- (b) - The 34 learning disabled participants will be seen initially for approximately one hour.
 - A subgroup of participants (n=15) will be involved in another session with physiological measurement of anxiety which will last approximately one hour.
 - The non-learning disabled group will complete the questionnaire and BAI independently.
-

11. Please state who will have access to the data and what steps will be taken to keep data confidential:

The proposer and the supervisor will have access to the data. Identification codes will be used during the analysis of the data to ensure confidentiality. There will only be feedback to the resource centre staff and carers if the participant becomes very upset during the session and it is felt to be in their best interests for a member of staff to be informed of this.

12. Please give details of how consent is to be obtained. A copy of the proposed consent form, along with a separate patient information sheet, written in simple, non-technical language, must be attached to this proposal form.

Consent will be obtained from both the participants themselves and their primary carer (i.e. relative or keyworker). The purpose and content of the study will be explained verbally initially. Participants will be provided with written information sheets which they will be asked to sign. They will be provided with a copy of this. Consent will also be sought from the Community Learning Disabilities Teams (CLDT's) and Resource centres for permission to contact their clients about the study. All information sheets and consent forms are attached.

13. Is the power of the study sufficient to answer the question that is being asked? Please indicate the calculations used for the required sample size, including any assumptions you may have made. (If in doubt, please obtain statistical advice).

The numbers of participants has been calculated on the basis of a power calculation at 0.8 using data from the Lindsay & Michie (1988) and Zung (1971) papers on the development of an anxiety scale at 2 standard deviations. This was calculated using the G-power programme (Faul & Erdfelder, 1992).

**14. What statistical tests will you apply to your results?
Please give details of proposed methods:**

The statistical tools used will include:-

- qualitative analysis of the focus group data for the derivation of potential scale items
 - item deletion and calculation of the α coefficient to determine the most useful questions
 - one-way ANOVA to consider differences between the three groups
 - Spearman's rho correlation to consider the relationship between self-report and physiological arousal
 - correlation to compare the scores of the non-learning disabled group on the scale under development with scores on the Beck Anxiety Inventory and Beck Depression Inventory
 - factor analysis to determine the structure of the subgroups within the scale
-

15. Scientific background to study (give a brief account of relevant research in this area with references):

Anxiety disorders are amongst the most common forms of psychological difficulties and there has been extensive research into the area attempting to understand the causes and maintaining factors involved in anxiety (e.g. Beck et al, 1988). As part of this research many scales have been developed which attempt to measure the level of anxiety a person experiences in a reliable and objective way. The form of these assessments has varied but includes diagnostic interviews which require expert administration and self report questionnaires. Different aspects of anxiety have been considered including specific phobias (e.g. FEAR questionnaire, I. Marks & A. Mathews 1979), worry (e.g. Penn State Worry Questionnaire, T. Meyer et al 1990), and differentiating anxiety from other types of psychiatric symptoms (e.g. Beck Anxiety Inventory, Beck et al 1988).

The difficulty in using these measures with a learning disabled population lie in the level of abstract reasoning, complex language and accurate memory which are required to complete these forms. Attempts have been made to adapt scales which were originally intended for the general adult population for use with people with a learning disability e.g. Zung Adapted Anxiety Scale (Lindsay & Michie, 1988) where the language used was simplified, the response choice was reduced from four choices to a yes/no dichotomy, and the questions were read out to the participant by a clinician. Adapting widely used scales makes the questionnaires more accessible to this population however because the questionnaire was not designed specifically for this client group there are difficulties such as whether the construct of anxiety is the same in people with a learning disability as in the general adult population.

In order to overcome some of the theoretical difficulties of abstracting findings from one population to another, a structured interview has been developed based on ICD-10 classification of symptoms. This diagnostic interview called the PAS-ADD (Moss et al, 1996) uses strategies such as a 'time anchor' (a memorable event which occurred in the participant's recent past) from which to rate occurrence of symptoms rather than a day of the week or a date. This inventory is comprehensive and overcomes many of the difficulties of adapting other forms however it has its own limitations. It needs to be administered by trained professionals such as psychiatrists or psychologists and its very comprehensiveness makes this time consuming, limiting its use in clinical and research work. It has a checklist version which is completed by the person's carer but this is dependent on someone else's opinion rather than the individual's experience.

Psychological treatment for anxiety has been used successfully with people with a learning disability (e.g. Lindsay & Morrison, 1996) and so identifying a population who are particularly vulnerable to anxiety could have beneficial results both in terms of targeting limited resources and helping people who may have difficulty expressing their needs clearly themselves.

There is a need for a self-report questionnaire which has been developed specifically for a learning disabled population, is valid, reliable and quick to administer. The current study aims to develop such a scale.

16. Does the research involve additional invasive procedures over and above the normal treatment of the patient? If so, are there any hazards associated with the procedure?

No

17. Please state any other potential hazards to participants arising from the research, their estimated probability (if possible) and the precautions to be taken to meet them:

None

18. Please describe any procedures which may cause discomfort or distress to participants, the degree of discomfort or distress entailed and their estimated probability:

It is possible that some of the participants may become upset while looking at the pictures. If a participant appears upset, they will not be shown any more pictures, they will be given the opportunity to discuss what is upsetting them and attempts will be made to calm them down. If necessary the session will be terminated and resource centre staff will be informed. It will be made clear to all the participants that they can leave the session at any point and there will be no consequences as a result of this, however it is not anticipated that any participants will become upset as participants will already have been screened for suitability prior to the sessions and will have consented to taking part.

19. Who are the proposed participants in the research (and controls if appropriate), and how are they to be selected? Please give details of age, sex, numbers involved and any other relevant details:

The proposed participants for the study are 34 male and female adults with a learning disability aged eighteen or over. They will consist of two groups, 17 participants with anxiety (as diagnosed by a psychologist or psychiatrist working in the CLDT and confirmed by the proposer using the PAS-ADD), and 17 participants who do not meet the criteria for clinical anxiety (as determined by the proposer using the PAS-ADD). Participants will be selected from names of potentially suitable people provided by the CLDT's and the resource centres. Their carers will be contacted and if they agree that we can contact their relative/client about the study, we will screen them for their suitability. The potential participants will then be contacted and asked if they would like to take part in the study (see letters and form attached). Anxious non-learning disabled participants aged eighteen or over, will be recruited from Adult Mental Health Clinical Psychology Departments in Glasgow.

20. Give names, strengths, doses and route of administration of investigational drugs to be used:

Not applicable.

21. Are the drugs to be used subject to the terms of:- Not applicable.

A Product Licence:

A Clinical Trial Certificate (CTC) or Certificate Exemption (CTS):

Is an unlicensed Product, but is registered under the DDX Scheme:

Which ever is applicable, please provide documentary evidence

22. Are the drugs used being given in accordance with the Product Licence, with the agreed protocol (in the case of CTX or DDX) or with the CTC?

Not applicable.

If no, give details:

23. Which manufacturer is organising the trial or supplying investigational drugs?

Not applicable.

24. If the trial is being undertaken in general practice and involves the supply of drugs, please state the arrangements for storage, labelling and dispensing.

Not applicable.

25. Are questionnaires to be used? If yes, a copy must be attached to this application form.

The PAS-ADD structured interview will be used to determine whether or not participants are clinically anxious. The Beck Anxiety Inventory (BAI) will be used with the non-learning disabled participants as part of the validation of the scale under development.

26. How is the project to be funded?

The only equipment needed for the project is a pulse-oximeter (details of which are attached) and this will be bought using funds from Prof. Espie’s research grant. Other costs are expected to be minimal and will be met by the proposer.

27. Please state any ‘interests’, ie. profit, personal or departmental, financial or otherwise, relating to the study. Details of payments per patient recruited, and/or any other remuneration details must be included.

There are no ‘interests’ relating to the study other than the proposer attaining her doctorate. No payment will be made to participants.

28. Will the research have revenue consequences for the NHS? If yes, please tick the box(es) applicable below:-

No

Nursing

Pharmacy

Medical Records

Laboratory services

Other clinical services of the Trust

Other

Which?

If you answer yes to any of these, please give details of the revenue consequences.

29. Please attach other relevant material: for instance, letters to subjects (which must be in simple non-technical language).

The information supplied above is to the best of my knowledge and belief accurate. I have read the notes to investigators and clearly understand my obligations and the rights of the subject, particularly in so far as to obtaining freely given informed consent. I also confirm that I have read and understood *“The Declaration of Helsinki”*

Date of Submission:

Signature of Principal Investigator:

.....

.....

Please find enclosed:

- Information sheets and consent forms for the participants
- Information sheets and consent forms for the Community Learning Disability Teams and Resource Centres

(See Appendix 2.1)

Major Paper

**PSYCHOMETRIC PROPERTIES OF A NEW SCALE FOR
MEASURING ANXIETY IN PEOPLE WITH A LEARNING
DISABILITY: THE GLASGOW ANXIETY SCALE FOR PEOPLE
WITH A LEARNING DISABILITY**

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Target Journal: *British Journal of Psychiatry*
(See Appendix 3.1)
Word Count: 4,441

Summary

Background

There is a shortage of reliable and valid tools for assessing psychopathology in learning disabled people. This study aimed to develop and psychometrically evaluate a self-rating scale to measure anxiety for clinical and research purposes.

Method

An item pool was generated from focus groups with learning disabled people, a review of the literature and clinician feedback. The GAS-LD was administered to 19 anxious and 16 non-anxious learning disabled people for further validation and appraisal of reliability. It was given to 19 anxious non-learning disabled people for cross-validation with the Beck Anxiety Inventory. Physiological concomitants were assessed using a pulse-oximeter.

Results

The GAS-LD successfully differentiated between anxious and non-anxious participants, had good test-retest reliability and internal consistency ($r=.953$; coefficient $\alpha =.96$) and was highly correlated with the BAI ($r=.72$, all $p<.001$). The correlation between the GAS-LD physiological sub-scale and changes in heart rate was modestly significant ($r=.47$, $p=.037$).

Conclusions

The GAS-LD offers a new, psychometrically robust approach to the appraisal of anxiety in this population.

Introduction

There has been limited research into the mental health problems of people with a learning disability, in spite of the high prevalence of disorder in this population (Eaton & Menolascino, 1982). Anxiety disorders are among the most common psychological difficulties and comprise a considerable proportion of research effort in the general adult field. However there is a dearth of research involving people with a learning disability. One reason for this is the difficulty in developing assessment tools due to communication and conceptual difficulties (see Mindham, 1999 for a detailed discussion). The aim of this study is to develop and evaluate a self-report anxiety questionnaire specifically for people with a learning disability. In addition to affective state, the study incorporates assessment of physiological concomitants of anxiety which it is hoped will corroborate the self-reporting of physiological symptoms. This feature may have particular application for people who have more limited communication skills.

Method and Results

In order to present a clear picture of the stages involved in the development of the Glasgow Anxiety Scale for People with a Learning Disability (GAS-LD), methodology and results will be integrated. The overall aim of this study was to develop a new measure of *anxiety symptomatology as experienced by people with a learning disability*. This is therefore primarily a psychometric study addressing issues of validity, reliability and scale sensitivity. It was also felt to be important to develop a measure which would be consistent with clinicians' clinical judgement and which would correlate with other scales and if possible with physiological measures of anxiety. See Appendix 3.2 for an illustration of the experimental design.

Development of an item pool for the GAS-LD

This was achieved by means of focus group discussions, a review of the literature and clinician feedback.

- *Focus groups*

The first stage of developing the questionnaire comprised two focus groups involving learning disabled people. It was felt that focus groups would generate key issues which people with a learning disability concern and the language that they may use to express their anxiety (see Morgan, 1988 for a discussion of the role and use of focus groups). The term 'worry' was used in a broad sense to elicit these areas of concern to the participants. In itself, it was not intended to indicate pathological 'worry' or to identify a stage in the cognitive processing of stimuli. In order to identify items, one resource centre was approached and two focus groups were arranged with those people willing to participate. Both groups comprised of four participants and one moderator (the author). The 8 participants had an average age of 41.5 years (range 26-64; s.d. 14.1) (See Table 1). There were 5 men and 3 women. One person had a moderate level of learning disability while the others had a mild level of learning disability. The group were asked prompt questions such as "Does anyone here worry about things?" and "What sort of things do you worry about?". The subsequent discussion was tape recorded and later transcribed. The moderator's role resulted in a high level of involvement, in attempting to include all the participants and keep the majority of the discussion focused on aspects of anxiety. Each session lasted about 45

minutes by which point all the participants had contributed and appeared to have nothing further to add about anxiety. All references to anxiety in the transcription of the discussions were highlighted and questions were then derived to reflect the issues raised, and the language used by the participants. The 20 derived items were included in the initial pool of questions.

- *Review of the literature*

The content of five widely used anxiety scales, (Beck Anxiety Inventory, Beck et al, 1988; Hamilton Anxiety Questionnaire, Hamilton, 1959; FEAR questionnaire, Marks & Mathews, 1979; Penn State Worry Questionnaire, Meyer et al, 1990; Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983) and three scales that were developed for use with a learning disabled population (Adaptation of the Zung self-rating anxiety scale, Lindsay & Michie 1988; Psychopathology Instrument for Mentally Retarded Adults (PIMRA), Matson et al, 1984; Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD), Moss et al, 1994;) were analysed. Anxiety related items were collated and items which were included in four or more of the questionnaires, n=18, were added to the pool of questionnaire items if not already present.

Pool questions were then organised into themes of worries, specific fears and physiological symptoms, to aid comprehension. It was decided not to reverse score any items as this would be confusing to respondents. It was felt that the validity of the responses to the questions was most important and could not be compromised.

- *Clinicians' feedback*

Once the items for the questionnaire had been collated from the focus group discussion (n=20) and the analysis of other questionnaires (n=12), the pool of items was given to clinical psychologists working with people with a learning disability and final year trainee clinical psychologists with experience of working with learning disabled people. Five clinical psychologists and 4 third year trainees gave feedback on the questionnaire. Their comments were considered and incorporated in the questionnaire as much as possible. Their comments led to 3 additional items being included and the wording of 4 other items being changed. The draft GAS-LD consisted of 35 items relevant to anxiety and is reproduced in Appendix 3.3. This has been annotated to indicate the source of each item.

Development of response format for the GAS-LD

The format of the response options was considered. Lindsay and Michie (1988) found that a 4 choice format was less reliable and too confusing for respondents and concluded that a 2 choice format where “the only response presentation which received an acceptable reliability correlation coefficient was the one in which the subject simply indicated presence or absence of anxiety symptoms” (p489) was the better format (test-retest reliability after 3 months was $\alpha=0.83$). However their 4 option response format may have been rather complex as it involved choosing between:- none or a little of the time; some of the time/sometimes; quite a lot of the time; and most of the time; the wording of which is quite complicated. Furthermore, clinical practice suggests that a simple dichotomy may be confusing for some clients, forcing them to make a choice and increasing the risk of perseverative errors. A simple dichotomy may also be insensitive to change in the frequency of symptoms over time or following treatment. In this study, it was felt therefore that the three response options; ‘never’ (0), ‘sometimes’ (1) and ‘always’ (2), would be the most valid. The draft GAS-LD thus provides a total score for the scale (0-70) but also could be considered as sub-totals for each section of Worries (0-24), Specific Fears (0-26) and Physiological Symptoms (0-20).

Psychometric properties of the GAS-LD

Validity

The procedure outlined so far would tend to support the content validity of the scale. The next step of the study was to look at the scale’s ability to discriminate levels of anxiety, and its relationship to other scales. This phase of the study required identification of three samples of participants, anxious people with a learning disability, non-anxious people with a learning disability and anxious people without a learning disability. The two learning disabled groups were required in order that the GAS-LD could be evaluated in terms of its ability to distinguish between anxious and non-anxious learning disabled people to determine its discriminant validity. The anxious non-learning disabled group was required to establish whether the GAS-LD was comparable with standard anxiety scales which have been developed for the general population to ensure the same dimension was being assessed and thus to evaluate its criterion validity. The BAI was chosen as the questionnaire for comparison as it has been carefully validated and is widely used (Beck, et al, 1988).

Concurrent validity was evaluated by measuring a physiological concomitant of anxiety and relating this to the Physiological subscale of the GAS-LD.

Method

It was estimated that a minimum of 17 participants per group ($n=51$ in total) would be required to detect if there was a significant difference between groups, based on data derived from Lindsay & Michie (1988) and Zung (1971) (G power programme at 0.8 power, $p<.05$ two-tailed). Participants were identified by clinical psychologists working in learning disability services in Glasgow in the case of all the anxious and some non-anxious learning disabled participants. Further non-anxious participants were recruited through several day centres. Participants were told that the study was about how people feel, especially about feeling worried or wound-up. It was made clear that they were free to refuse to take part or to leave if they wanted to. The appropriate consent format was approved by the local ethics committee. The referring clinicians and day centre staff were given guidelines as to the suitability of participants. The criteria were:- some verbal language and a reasonable level of comprehension, clearly anxious or not anxious, no diagnosis of autism or dementia, and people who they thought would like to take part in a study. All the participants were then screened using the PAS-ADD, a standard assessment procedure for evaluation of psychiatric disorder in people with a learning disability. It was developed to provide the information required to make an ICD-10 diagnosis of different disorders. Thus those people meeting ICD-10 criteria for anxiety were allocated to the anxious group. The diagnoses were Generalised Anxiety Disorder ($n=13$), Panic Disorder with Agoraphobia ($n=4$), Panic Disorder without Agoraphobia ($n=1$) and Specific Phobia ($n=1$). Participants who met the criteria for other disorders would not have been included however this did not arise. Two people's results were not included as they did not appear to understand the questions. Of the 50 people approached to participate by their psychologist or day centre staff, 10 people refused. The reasons varied from being too anxious to take part, to being busy with other things. Some of the anxious learning disabled participants who were approached and refused to take part may have had a higher level of social anxiety. No one dropped out of the study once they had agreed to take part.

Initially, an additional section of 10 screening items was included in the questionnaire. The intention of this section was to highlight other mental health problems such as depression,

sleep problems and memory problems which may complicate a diagnosis of anxiety. However the PAS-ADD also covered these areas, so, in order to avoid duplication of available tools, it was later removed from the questionnaire.

The learning disabled people were allocated to the anxious or non-anxious groups on the basis of the referring clinician's diagnosis, and an assessment using the relevant components of the PAS-ADD. One person, referred by day centre staff, who was initially in the non-anxious group, was reassigned to the anxious group on the basis of her PAS-ADD assessment. The non-learning disabled participants had all been referred to an adult psychology department for anxiety related difficulties and were asked if they would be willing to complete the GAS-LD and the BAI, along with a consent form, as part of research study.

The recruitment procedure identified 69 people of whom 59 agreed to participate (anxious learning disabled group $n=19$, non-anxious learning disabled group $n=16$, non-learning disabled anxious group $n=19$ and focus group $n=8$) though 3 participants were involved in both the focus group and experimental groups. The male to female ratio was 31:28. The average age of participants was 36.93 years (range = 17-69: s.d.=11.82) (see Table 1). Thirty three participants had a mild degree of learning disability and 7 had a moderate degree of disability. There were no significant differences between the experimental groups in terms of age, gender or degree of disability. It is noteworthy however that fewer females emerged with anxiety in the learning disabled group compared with the non-learning disabled group.

(Insert Table 1 here.)

a) Content Validity

Having identified a suitable group of participants, the validity of the scale was assessed in 4 ways. The first of these stages was to evaluate further the content validity or representativeness of the GAS-LD further. The items ($n=4$) which were scored as 1 (sometime) or 2 (always) by fewer than 40% of the anxious respondents were removed. The exception to this were the physiological items ($n=1$) which were so frequently reported by the anxious participants that they were removed if endorsed less than 75% of the time. Three

of the items which were seldom endorsed apparently were confusing. One of these items was clarified and 2 were removed. The final questionnaire, which is in Appendix 3.4, therefore comprised 27 items each of which relate to an aspect of anxiety. (See Appendix 3.5 for a list of the items removed from the draft GAS-LD and the reasons for their removal.)

b) Discriminant Validity

The ability of the GAS-LD to discriminate between the 3 experimental groups was investigated by means of One-way ANOVA. As can be seen in Figure 1 the questionnaire appeared to discriminate between the anxious (n=38) and non-anxious (n=16) groups in terms of levels of anxiety reported. This was confirmed by One-way ANOVA ($F=51.99$; $p<.001$) and Scheffe post hoc tests demonstrated there was a significant difference between each of the 2 anxious groups and the non-anxious group (both $p<.05$). There was no significant difference between the 2 anxious groups (See Figure 1).

(Insert Figure 1 here)

c) Criterion Validity

The GAS-LD was completed by 19 people with anxiety who did not have a learning disability along with the Beck Anxiety Inventory. A scatter plot of the relationship between the scores on GAS-LD and BAI is reproduced in Appendix 3.5 which illustrates the correlation between scores on the GAS-LD and the BAI. Since the sample of non-learning disabled participants was relatively small (n=19), data were analysed using Spearman's correlation (2-tailed). This analysis revealed $\rho = .72$, significant at $p = .001$ indicating good criterion validity.

d) Concurrent Validity

In order to investigate the relationship between the physiological symptoms sub-scale of the GAS-LD and physiological arousal experienced, an experimental procedure was devised. This comprised a baseline condition during which the experimenter chatted to the participant; experimental phase 1 when the GAS-LD was administered and the participant was asked to talk about anxiety provoking experiences they had referred to in the GAS-LD;

experimental phase 2 when six pictures were shown which were of a dog, a bee, a spider, a snake, an electrical storm and a doctor from the Specific Fears section of GAS-LD (see Appendix 3.6) and the participants were asked to describe what they were looking at; and finally a wind down period to allow a return to the baseline condition. The pictures were chosen to represent specific fears which had been commonly reported in the development of the GAS-LD and were included in the Specific Fears section. Each picture was shown for approximately one minute. The length of the time periods varied depending on the participant but the baseline and wind-down periods were both approximately 5 minutes in length.

A physiological concomitant of anxiety, pulse rate, was measured in 15 participants using a pulse-oximeter with a finger cuff which attached to the dominant wrist with a microprocessor in the form of a wrist watch (see Appendix 3.7). The pulse-oximeter was the Minolta Pulsox-3i (Stowood Scientific Instruments) which has a memory function and compatible software for Windows-based analysis of the data. This measured the pulse rate, at 5 second intervals. Pulse rate was measured throughout the four different stages of baseline, experimental phases 1 and 2 and wind-down period. The baseline and wind-down periods were used to determine the participants' pulse rate in the absence of anxiety provoking stimuli. It was predicted that the 2 experimental phases would cause a greater increase in pulse rate, relative to baseline, in the anxious participants. To analyse the data, the participants average pulse rate and standard deviation for each experimental period was calculated. This method of analysis was chosen as it has been used successfully in other areas of research for example Dunn et al, (1996).

A representative sample from the anxious learning disabled group ($n=7$) was compared with a representative sample from the non-anxious learning disabled group ($n=8$) for the difference between the scores of the physiological sub-scale on the GAS-LD and change in pulse rate during the questionnaire and picture time periods. There was a significant correlation between these (Spearman's two-tailed ($n=15$), $r=.515$, $p<.05$) as shown in Figure 2, with the participants who had higher scores on the physiological sub-scale experiencing a greater increase in pulse rate over the experimental phase. This suggests that the physiological component of the GAS-LD has reasonable concurrent validity.

(Insert Figure 2 here.)

The difference in pulse rate between the anxious and non-anxious groups was just short of reaching significance (Mann-Whitney $U=11.5$, $p=.054$) suggesting that there is variation within the anxious and non-anxious groups as to their experience of physiological symptoms during the experimental period. There was no significant difference between the anxious and non-anxious groups in terms of the average pulse rates ($F= 1.620$; $p= .225$) across the 4 time periods or in the degree of variance in pulse rate, i.e. the standard deviation, as analysed using a repeated measures ANOVA ($F= .003$; $p= .939$). However there was a trend for the anxious participants' pulse rate to increase during the anxiety provoking time periods which was not evident for the non-anxious participants as illustrated in Figure 3. In a larger sample this trend may have been significant. It is noteworthy that the anxious group overall, had a lower average pulse rate than the non-anxious group however it is unlikely that this would be evident in a larger sample.

(Insert Figure 3 here.)

Reliability

a) Test-retest reliability

The GAS-LD was re-administered to 17 respondents from the anxious and non-anxious learning disabled groups approximately 1 month later. The test -retest reliability of the questionnaire, assessed by Pearson product moment correlation was highly satisfactory ($r= .953$, $p<.0001$, two-tailed).

b) Internal consistency

The GAS-LD was found to have high internal consistency as measured by coefficient α when administered to the learning disabled participants ($\alpha= .96$ when $n=35$). The split-half correlation for the whole scale was .93. The coefficient α for part A, Worries, was .924, the coefficient α for part B, Specific Fears, was .804, and the coefficient α for part C,

Physiological Symptoms, was .904. The range in internal consistency for the whole scale as measured by alpha if item deleted was between .954 and .959.

Factor structure of GAS-LD

Principal Components Analysis (PCA) using varimax rotation revealed that 45% of the total variance (or 62.5% of the explained variance), was accounted for by one factor. By taking a conservative factor loading of .45, only two of the 27 items were not explained by the first component. These items were ‘Are you scared of spiders?’ (Question 15) and ‘Do you feel scared in lifts or escalators?’ (Question 13). These items are both very specific so it was felt that in future by broadening their scope to ‘Are you scared of insects?’ and ‘Are there any other things you are scared of?’, there might be a higher level of correlation between these items and the rest of the scale. See Table 2 for Factor 1 of the Principal Components Analysis. Five other factors were generated by PCA however none of these explained at least 10% of the variance (maximum=7.5%) (see full component matrix in Appendix 3.8). Furthermore they add little of explanatory value to the structure of the scale. It appears therefore that a single factor of “anxiety”, comprising 25 items, yields the best model for the GAS-LD.

(Insert Table 2 here.)

Discussion

The purpose of this study was to develop and psychometrically evaluate a self-rating scale to measure anxiety in people with a learning disability, for use in clinical and research settings. This has resulted in the development of the Glasgow Anxiety Scale for People with a Learning Disability (GAS-LD) which has been shown to be a potentially useful measure.

The intention in the development of the GAS-LD was to ensure the scale was applicable to learning disabled people rather than adapting a general measure for use with this client group. There has been little work done on the construct of anxiety in people with a learning disability, with the assumption being made that it is the same as in the general adult population. While the development of this scale has been reliant to some extent on generally

accepted constructs of anxiety, in the reference to other literature and the use of the BAI as part of the validation process, attempts have been made to work directly with learning disabled people in the development and validation of the scale.

Development of the Item Pool

The GAS-LD has been constructed specifically for a learning disabled population, through consultation with learning disabled people, clinicians working in the field and with reference to other literature. The different sources for items ensured a combination of individuals' experiences and expertise with an underlying theoretical basis from reference to other literature.

Development of Response Format

The 3 option response format was easy to use, with participants frequently spontaneously rating their level of symptoms in terms of never, sometimes or always. This suggests that these were categories they were familiar with and understood. This is supported by the good test-retest reliability, as a poor understanding of the response format would have led to a poorer test-retest reliability.

The format of the GAS-LD was found to be user-friendly and only took between five and ten minutes to administer allowing it to be used easily within clinical sessions, research studies and for screening purposes.

Psychometric Properties of the GAS-LD

Validity

The GAS-LD was carefully and methodically developed resulting in high face and content validity. Results suggest that the GAS-LD can reliably distinguish between anxious and non-anxious people with a learning disability when categorised on the basis of a clinicians' judgement and using the PAS-ADD structured interview. It is also highly correlated with the BAI for an anxious non-learning disabled group suggesting the same dimension is being assessed.

Concurrent Validity

The utility of measuring physiological concomitants of anxiety was not proven in this study however it was felt that it was a useful component as, to our knowledge, physiological concomitants have not been measured for scale development with learning disabled people. The participants did not object to wearing the pulse-oximeter during the study. It was difficult to standardise the experimental trials as some participants talked at greater length about their experiences than others. Although there was a significant correlation between level of physiological symptom reporting on the GAS-LD and changes in pulse rate during the questionnaire and picture time periods, by looking at a graph of this data (see Fig. 2), it is apparent that this result is misleading. Only 2 of the anxious participants had changes in pulse rate from the baseline to experimental period that were greater than those seen in the non-anxious participants, and this number is too small to draw meaningful conclusions from. However what is apparent from Fig. 2 is that some of the participants had a drop in pulse rate during the experimental period. If this period was not anxiety provoking, it would be reasonable to assume that there would be no change in pulse rate. The drop may suggest that the participants' pulse rate was continuing to fall to a baseline level during the experimental period. If this is the case, future investigations should ensure that a sufficiently long baseline period is incorporated into the experimental design.

The change in the participants' pulse rate over the experimental periods did not differentiate between anxious and non-anxious participants. However it is evident from Figure 2 that there is a trend towards the anxious participants experiencing a greater increase in pulse rate than the non-anxious participants. Although the numbers are too small to make general conclusions, it is possible that there is considerable variation in the extent to which anxious people experience physiological symptoms and this may relate to the type of anxiety experienced, for example, people with generalised anxiety disorder may experience fewer physiological symptoms than people with panic disorder. It may be fruitful for another study to investigate this with larger numbers of participants in discrete sub-groups. Another observation which may have affected the results was that several of the non-anxious group were frightened of spiders or other specific items which, while not sufficiently severe to place them in the anxious group, may have lead to an elevation of pulse rate when looking at a picture of the feared stimulus.

This study has provided a preliminary trial of one method of measuring physiological concomitants of anxiety in people with a learning disability. While the results are difficult to interpret in part due to the small numbers and heterogeneous group, further work on the identification of physiological concomitants could provide corroborative evidence of symptoms experienced. It may also result in an alternative form of assessing physiological symptoms of anxiety in people with very limited communication skills.

The Scale developed fulfils clinical and pragmatic roles in measurement rather than providing a conceptually valid scale. The questions in the scale primarily refer to Trait anxiety rather than State anxiety. It would be useful to develop a scale which assesses State anxiety as well by asking the participant how s/he feels at the time of the assessment. Spielberger et al (1970) found that the connotations of some words emphasised either Trait or State responding. For example “I feel upset” was found to be good for assessing State where as “I tire easily” tended to elicit more enduring Trait aspects.

It is apparent that the scale includes items pertaining to a variety of diagnoses and the components identified in the three systems model, thoughts, emotions and physiology. Conceptually the scale would be improved by identifying each of these components and being able to consider them separately. However as discussed in Mindham (1999) the lack of evaluation of conceptualisations of anxiety in the learning disabled population makes this process both difficult and premature. This scale is intended as a tool to start further consideration of anxiety in this population and as such is likely to need considerable amendment as the field develops.

Reliability

The findings show that the GAS-LD has a high level of internal consistency and test-retest reliability. One important area to consider further would be ‘inter-administrator’ reliability as all the administration of the GAS-LD was done by the same person, the author, which potentially may have affected the reliability. In extending the evaluation of the GAS-LD to people with a more severe degree of learning disability, it would be interesting to see if the reliability was still good.

Factor Structure

All but 2 questions loaded on one factor. This indicates that all the items tap into different aspects of the same construct which was identified as “generalised anxiety”.

Limitations

There were a number of limitations of the study:-

1. The development of a well validated conceptualisation of anxiety in people with a learning disability was beyond the scope of this study though as a result the validity of the conceptual basis of the scale is limited. However the results of the study suggest the scale has strong clinical validity.
2. The participants primarily had a mild level of disability, with a few people with moderate level of disability. It would be useful to evaluate the utility of the GAS-LD with people with a more severe level of impairment. It is possible that some of the questions would need to be more concrete for that purpose.
3. The scale was not evaluated in terms of its ability to distinguish people with symptoms of anxiety from people with symptoms of other disorders, such as depression, however this would be a useful development.
4. At the development stage the issue of State versus Trait anxiety was not adequately addressed and as a result the wording of the questions has lead to Trait rather than State anxiety being assessed. Future work could address the assessment of State anxiety which would be particularly important in the evaluation of change during and following treatment.

Clinical Implications

The development of the GAS-LD has several implications for both clinical and research work with learning disabled people:-

1. The preliminary trial of a methodology for assessing physiological concomitants, while inconclusive, provided useful information about future methodology, in particular the need for larger numbers and relatively homogeneous populations.
2. The GAS-LD is quick and easy to administer making it suitable for use as a screening tool or as part of a battery of questionnaires in research or clinical work.

Conclusion

The development and evaluation of the GAS-LD has provided promising results in terms of the scale's validity and reliability. It is hoped that it will become a useful measure for both clinical and research practice in the future. It may be used in combination with other tools such as the PAS-ADD diagnostic interview schedule in advancing our understanding of psychopathology in people with a learning disability.

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Table 1. The characteristics of participants by experimental group (total n=59).

Group	Number of Participant s	Age	Gender male:female	Degree of disability mild:moderate
Anxious Learning Disabled Pp	19	37.6 (24-69; s.d.=10.6)	12:7	16:3
Non-anx Learning Disabled Pp	16	34.9 (22-54; s.d.=10.4)	8:8	13:3
Anxious Non- learning Disabled Pp	19	34.5 (17-57; s.d.=12.9)	8:11	N/A
Focus Group Pp	8	41.5 (26-64; s.d.=14.1)	5:3	7:1

Table 2. Factor 1 of the Principal Components Analysis with item loadings. Significant loadings ($p > .45$) are presented in bold typeface.

Question		Factor 1 - Generalised Anxiety
1	Do you worry a lot?	.804
2	Do you have lots of thoughts that go round in your head?	.809
3	Do you worry about your parents/family?	.677
4	Do you worry about what will happen in the future?	.716
5	Do you worry that something awful might happen?	.835
6	Do you worry if you do not feel well?	.747
7	Do you worry if you are doing something new?	.670
8	Do you worry about what you are doing tomorrow?	.578
9	Can you stop worrying? (reverse score)	.751
10	Do you worry about death/dying?	.701
11	Do you get scared in the dark?	.540
12	Do you feel scared if you are high up?	.487
13	Do you feel scared in lifts or escalators?	.419
14	Are you scared of dogs?	.476
15	Are you scared of spiders?	.321
16	Do you feel scared going to see the doctor or dentist?	.544
17	Do you feel scared meeting new people?	.668
18	Do you feel scared in busy places?	.738
19	Do you feel scared in wide open spaces?	.536
20	Do you ever feel very hot or sweaty?	.659
21	Does your heart beat faster?	.702
22	Do your hands and legs shake?	.821
23	Does your stomach ever feel funny, like	.640

	butterflies?	
24	Do you ever feel breathless?	.757
25	Do you feel like you need to go to the toilet more than usual?	.461
26	Is it difficult to sit still?	.721
27	Do you feel panicky?	.899

Figure 1. The Mean GAS-LD scores with error bars for anxious and non-anxious participants

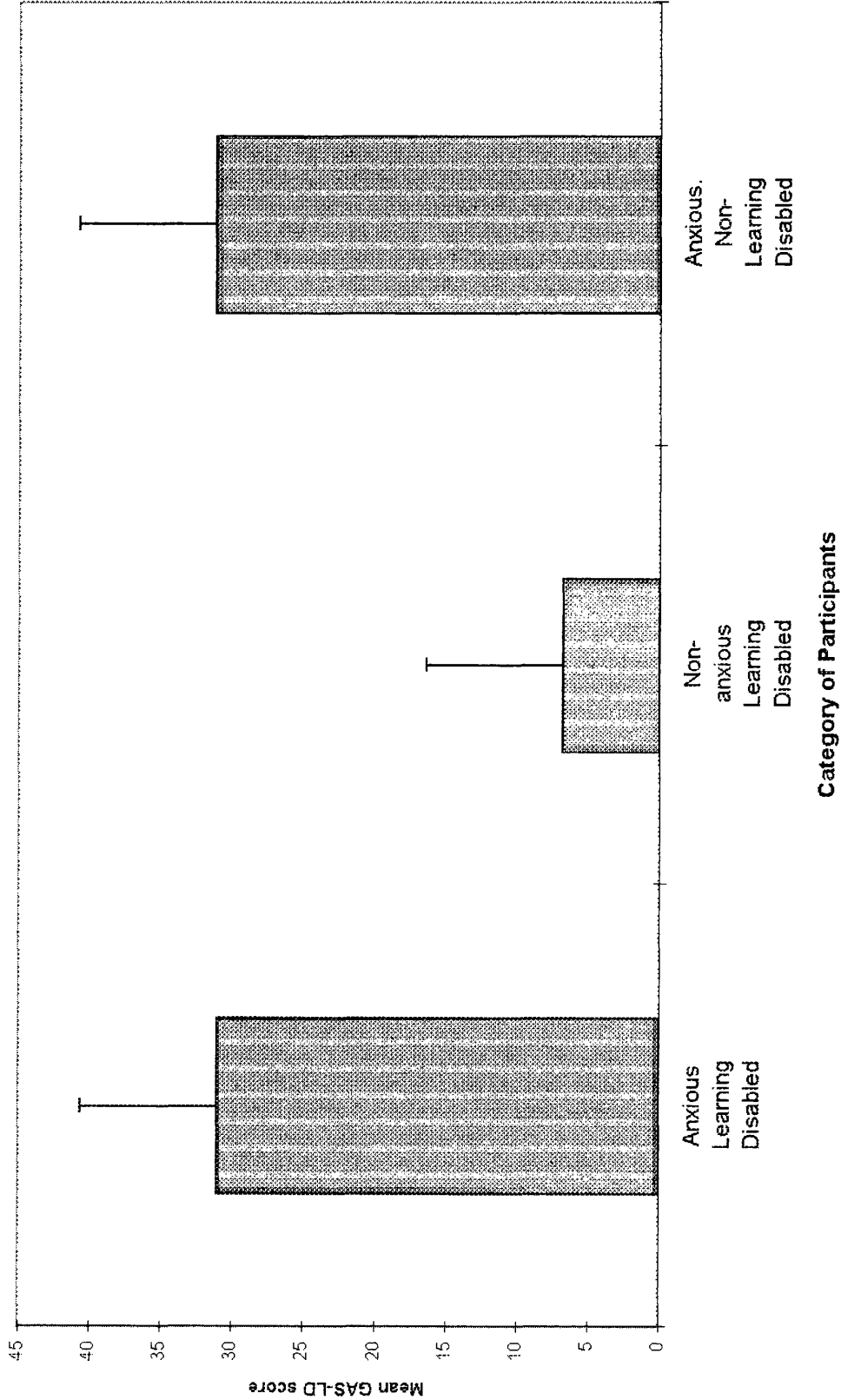
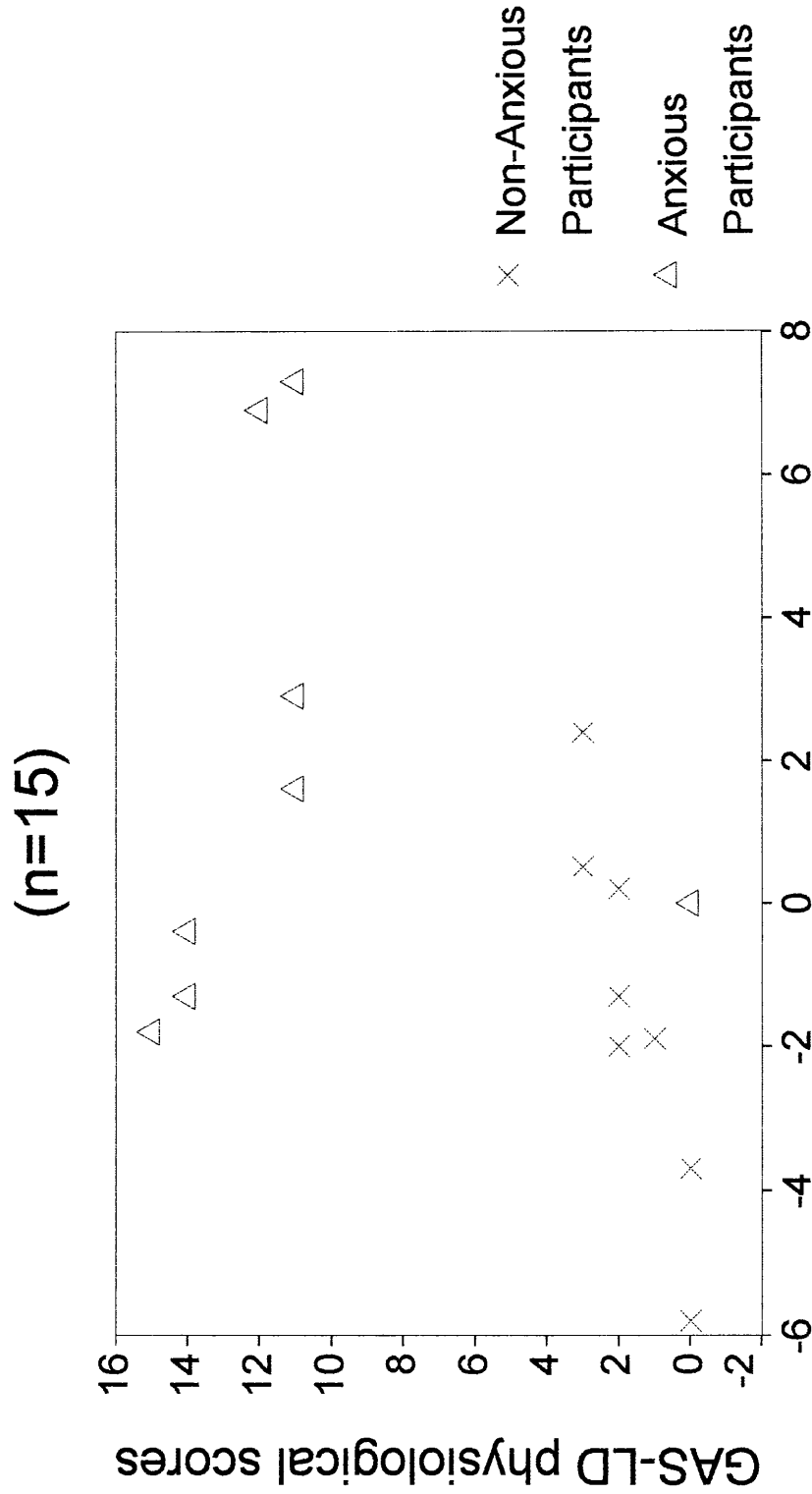
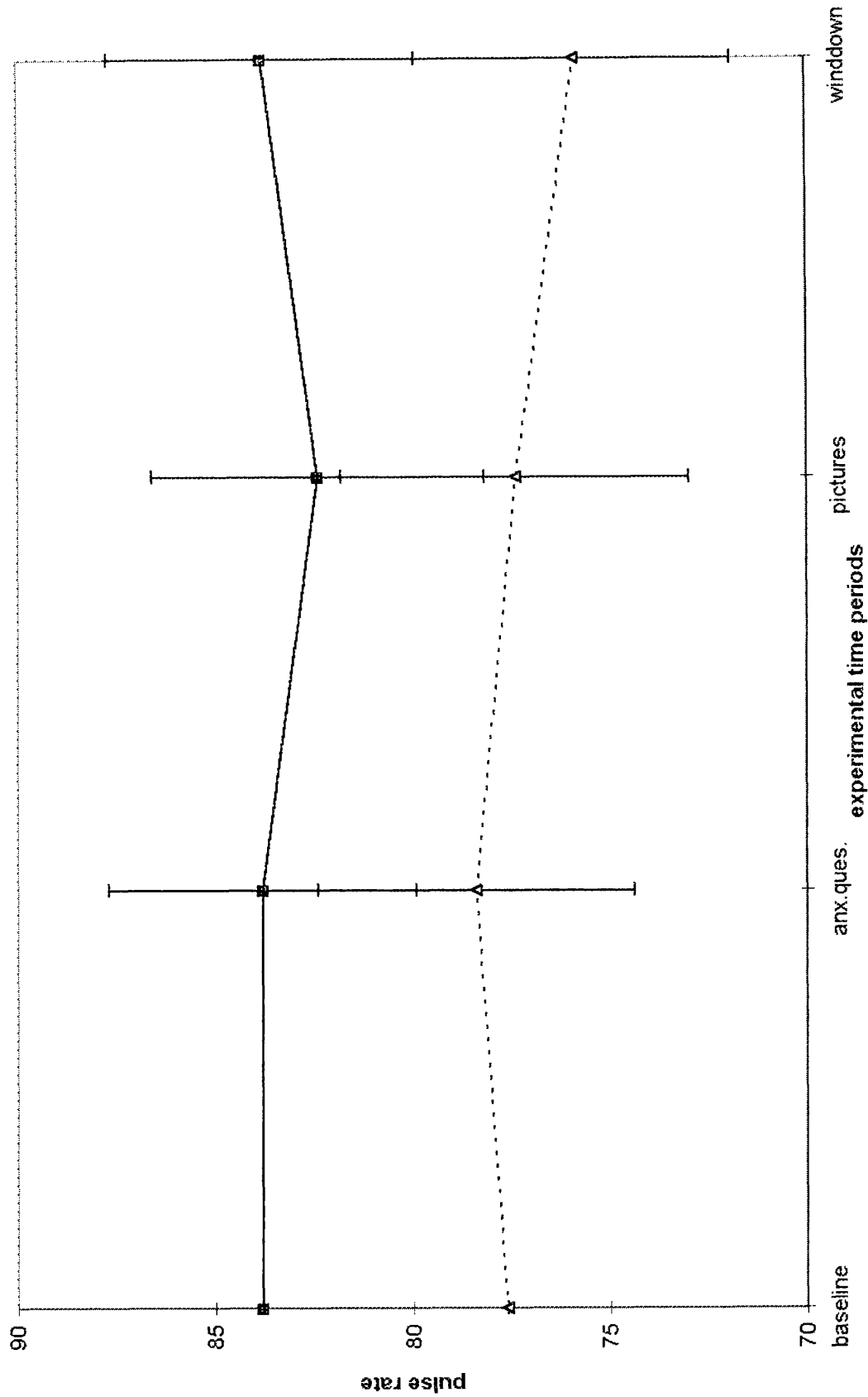


Fig.2 GAS-LD physio. scores in relation to pulse rate changes in the 2 experimental grps



Diff. between pulse rate in experimental and baseline phases

Figure 3. Comparison of mean pulse rate (with error bars) during experimental time period for anxious and non-anxious learning disabled participants (n=15)



Small Scale Project

AN EVALUATION OF THE PRIORITY REFERRAL SYSTEM TO A CLINICAL PSYCHOLOGY DEPARTMENT IN ADULT MENTAL HEALTH

AN EVALUATION OF A PRIORITY REFERRAL SYSTEM

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Target Journal: *Journal of Mental Health* (See Appendix 4.1)

Word Count: 3,290

Summary

An evaluation of the priority referral system involved the assessors in Dykebar psychology department (clinical psychologists, a counsellor and psychology assistants), evaluating the prioritisation of referrals made to the department, on the basis of the referral letter and again following an initial assessment. The levels of agreement between referrers and assessors rating of priority was high for 'soon' and 'routine' referrals, but low for 'urgent' referrals. Other aspects of the prioritisation process considered included age, sex, attendance and the types of presenting problems. Recommendations were made regarding giving referrers guidelines about priority referrals and introducing a department allocation meeting to screen referrals.

Introduction

Waiting lists within mental health services and clinical psychology in particular have long been an area of concern. The 1993 Division of Clinical Psychology report on waiting lists in the NHS calculated that 44.2 % of psychology referrals are made to departments with waiting lists of six months or more. Startup (1994) estimates that there may be as many as 28,000 people waiting for appointments with psychologists in the UK and suggests that this number would increase if waiting lists were shorter.

The effects of long waiting lists are apparent in different areas through the effect on psychologists morale, other professions view of psychology and, most importantly, the effect on clients. For psychologists there is considerable frustration associated with not being able to manage their caseload well or feeling that the service provided is not acceptable in terms of response time. Another aspect of this is feeling obliged to take a client on for treatment regardless of the appropriateness of the referral because they have waited so long to be seen (Robertshaw & Sheldon, 1992). Chadd and Svanberg (1994), in a survey of GP's perceptions of clinical psychologists, found that psychologists were seen as less accessible than all other mental health services apart from psychotherapy. The implication of this may be referral to other services which may not be the most appropriate form of treatment (Burton & Ramsden, 1994). Clearly this is an aspect of the service which needs to be addressed.

Considerable time and effort has been expended in attempts to reduce waiting lists through changes in service structure and in clinical practice. Ideas proposed have included opt in systems (e.g. Startup, 1994:), 2+1 models of intervention (Barkham & Shapiro, 1989), and assessment prior to assignment to waiting list (Geekie, 1995). However there have been drawbacks associated with all these practices (e.g. see Segar & Jacobson, 1991 for a critique of 2+1 systems). In a review of the effect of an opt-in system, Chiesa (1992) found that although there was a significant reduction in non-attendance, some clients may have been inhibited from contacting the department, finding the system 'distancing' and uncaring. Although reducing waiting times and increasing the efficiency of service are important, making the service less accessible to those in need is not a satisfactory solution.

Within Dykebar Clinical Psychology Department various approaches have been implemented with some success including; increasing group work, an interdisciplinary anxiety management service, sending information about the nature of clinical psychology with a letter about expected waiting time, and peer review of extended therapy cases (clients who have been seen for 15 sessions or more). However, there is still a long waiting list and other measures need to be considered. One aspect of the service that there was interest in reviewing is the priority referral system as, at times, it was resulting in the routine waiting list coming to a virtual standstill while 'urgent' and 'soon' referrals were seen. An audit of referrals (Collins, 1996) showed that between January 1st and March 31st 1996, 15.2% of the total referrals were 'soons' (to be seen within 9 weeks of referral) and 6.3% were 'urgents' (to be seen within 3 weeks of referral). Only 61% of 'urgent' referrals attended their first appointment in spite of their appointment being within 3 weeks of their referral. This raises the question of how appropriate these referrals are and if there is a better way of organising the system. Staff were also concerned that there were people on the routine waiting list who should be seen much more quickly than the current 24 week wait allows.

There is considerable variation in the proportion of priority referrals from different GP practices suggesting that GPs may be unclear about the type of service the psychology department is offering and be using different referral criteria for deciding whether or not someone requires a priority appointment. Burton and Ramsden (1994) asked GPs to indicate who they thought was the most appropriate mental health professional to refer people with a range of different diagnostic labels. There was a wide range of opinion suggesting that there is a need to inform some GPs about the role of a clinical psychologist within a mental health service and the types of problems that psychological intervention is particularly appropriate for. If GPs are struggling at times to decide who is appropriate to refer, it is likely that they also struggle to decide who requires a priority referral. There was also concern that some GPs or clients may be misusing the system to get round long waiting lists with the result that other clients were having to wait longer still.

It was agreed that a more extensive audit of priority referral patterns was required, information from which could then be used to provide GP's with guidelines for what appropriate priority referrals might be.

Aims

The aim of this project is to look at the way in which referrers use the priority referral facility. A number of questions were considered:-

1. Are referrers using the facility consistently?
2. What scope is there for altering this system?
3. Is there a need to inform GPs about the 'priority' referral system?

An evaluation of the priority referral system would answer these questions and may suggest ways of changing the system so that it is more time efficient.

Method

The referrer often only has a limited amount of information (especially in the case of GP's) on which to base their referral. It therefore seemed appropriate to assess the referral prior to treatment otherwise the psychologist may have information which was not available to the referrer. There was insufficient information in some referral letters to assess whether or not it should be a priority referral so it was felt that an evaluation of the appropriateness of the referral should be made by the psychologist both from the referral letter and following an initial assessment.

A questionnaire (see Appendix 4.2) was devised which was completed for every initial appointment offered in the department. This was filled out by the person conducting the initial assessment and was completed whether or not the person attended. The questionnaire was in two parts, the first part involving demographic details such as the patients age and presenting problem. The second part involved an evaluation by the assessor, of whether the patient should be seen urgently, soon or routinely. This judgement was made first on the basis of the referral letter, and then after the initial assessment. This section also required the assessor to indicate why the referral was or should have been seen as a priority. If this categorisation is found to be useful, it will be sent to referrers to give them some guidance as to the types of referrals psychologists think require a priority referral.

Practicalities

There are four clinical psychologists and one counsellor in the department who conduct the bulk of initial assessments. Psychology assistants assess people who are referred to the

department to attend anxiety management groups. The questionnaire was filled out by both qualified staff and assistants for all new people referred to the department.

The data was collected between 16th June and 16th August 1997.

Results

1. *Demographic Results*

- Referrals

During the specified time period, 121 questionnaires were completed for all the people offered appointments in the department. Of these referrals 72 were ‘routine’, 30 were ‘soon’ and 15 were ‘urgent’. In addition there were 4 people who had originally been referred routinely but whom the referrers felt subsequently needed a priority appointment (See Figure 1).

(Position of Fig. 1)

- Sex

The sex ratio of people referred was 43% males : 57 %females. There was variation within the categories with proportionally more women being referred who required a ‘soon’ appointment and more men requiring an ‘urgent’ appointment (See Figure 2).

(Position of Fig. 2)

Age

The age range was 16 - 72 years but the largest number were in the 26-35 age group (37% of total number referred). However the 16-25 age group had the largest proportion requiring a ‘soon’ appointments and the 56-65 age group the largest proportion requiring an ‘urgent’ appointment (See Table 1).

(Position of Table 1)

- Source of referral

The majority of referrals came from general practitioners (67%), the others coming from

psychiatrists (26%) and other hospital doctors (6.6%).

- Attendance

76% of the people offered appointments attended with 1.6% cancelling and 22.3% not attending. This pattern varied according to the urgency of the referral with the highest attendance rate of 86.6% for people offered ‘urgent’ appointments and the poorest attendance of 70% for people offered ‘soon’ appointments (See Table 2).

(Position of Table 2)

- Waiting Time

The waiting time ranged from 0-36 weeks with an overall average of 15.2 weeks. The average wait for someone referred for an urgent appointment was 5.4 weeks instead of the recommended 3 weeks, 8.6 weeks for ‘soon’ appointments and 20.3 weeks for routine appointments.

- Presenting Problem

The majority of referrals were labelled as anxiety (24%), depression (16.5%) and relationship problems (6%) based on a table of diagnoses drawn up by the assessors as the most frequently occurring problems. A further 21% fell into the ‘others’ category which included eating problems and sexual abuse issues. A proportion were described as having a combination of difficulties for example 10% were described as suffering from both anxiety and depression (See Table 3).

(Position of Table 3)

When the presenting problem was considered in regard to the priority of the referral it was found that the largest proportion of routine referrals were for people with anxiety difficulties (32%). In contrast the largest proportion of people referred requiring ‘soon’ or ‘urgent’ appointments had a combination of difficulties (46.6%) (See Table 4).

(Position of Table 4)

- Comparison with previous audit results

A smaller number of people were seen per month during the time period studied in 1997 than were referred to the department per month during the audit period in 1996. Within the people assessed in the department in 1997 there was a higher proportion of priority referrals than were referred in 1996 (See Table 5).

(Position of Table 5)

Of the people referred as requiring a priority appointment, in 1997 a smaller proportion of the urgent referrals did not attend than in 1996 (13.3% compared with 22.3%), but a larger proportion of the soon referrals did not attend in 1997 than in the 1996 sample (26.6% compared with 7.2%) (See Table 6).

(Position of Table 6)

2. *Descriptive Results*

- Level of agreement between referrer and assessor prior to assessment

There were high levels of concordance between referrers and assessors of people referred for routine or soon appointments (92% and 83.3% respectively). There was a low level of agreement about people who had been referred requiring an urgent appointment with only 33.3% of assessors agreeing with the referrers' categorisation. The assessors thought that 33.3% should have been referred as requiring a 'soon' appointment and 33.3% should have been given a routine appointment (See Figure 3).

(Position of Figure 3)

- Level of agreement between referrer and assessor following assessment

There was high concordance between the referrer and the assessor for referrals categorised as routine (98%) and soon (86%) but poor concordance for referrals categorised as urgent (31%) where the assessors felt that 40% of these referrals should have been categorised as soon and 27% should have been routine. Of the referrers who indicated a priority appointment was necessary but the assessor did not agree, 11 were general practitioners and 4 were psychiatrists.

- Level of agreement between assessors ratings prior to and following assessment

There was high concordance between the assessors rating prior to assessment and following assessment. Of the referrals where the client attended for an assessment appointment, there was a 98% level of agreement for routine referrals, 95% level of agreement for 'soon' referrals and an 82% level of agreement for urgent referrals.

- Usefulness of categories of reasons for priority referrals

A table was drawn up which listed a number of possible reasons for a priority referral. Of the 'urgent' referrals there was only one out of fifteen which did not fit into the suggested reasons for priority referrals and two where the reason for the referral being a priority was unclear. For the 'soon' referrals, there were five referrals out of thirty which did not fit into the suggested reasons for priority referrals and two where the reason for a priority referral was unclear. For the referrals that were categorised as urgent but the assessor felt should have been 'soon' instead, the person often had severe but long standing problems. Where the assessor felt the referrals should have been 'routine', the reason for a priority referral was usually not clear.

Discussion

There is a larger proportion of priority referrals in the present audit. Several members of staff were on annual leave during this period resulting in fewer new clients being seen. As 'urgent' and 'soon' referrals were given priority, fewer people from the routine waiting list were seen.

More women were seen than men though more men were referred as requiring an urgent appointment. The trend of more women receiving psychological services has been observed

and discussed (Lindsay, S.J.E. and Powell, G.E., 1994). There were people referred across the age range but more people were referred from the 26-35 age range. Again this may in part reflect generational differences in the acceptability of psychological interventions as well as variation in difficulties experienced.

Attendance at appointments was quite good, ranging from 70% for 'soon' appointments to 86.6% for urgent appointments. Attendance for urgent appointments was surprisingly good, going against clinicians impression that people seen urgently are more likely to DNA however as this group were seen, on average, within 5.4 weeks of referral, it is reasonable to expect good attendance. There is quite a difference between the attendance patterns across referral type in the present audit and the one conducted in 1996 when the DNA rate for people offered urgent appointments was much higher (22.3% compared with 13.3% in 1997) however as there was a corresponding increase in the DNA rate among people offered a soon appointment in 1997 it may be that the priority appointment DNA rate was similar in both time periods. The average waiting time for priority referrals is slightly distorted as two referrals were re-categorised by the assessor prior to an initial appointment and allocated a 'soon' rather than an 'urgent' appointment and so seen within 9 weeks as opposed to 3 weeks.

As expected, the most common difficulties that people were referred with were anxiety and depression followed by relationship problems. There were a significant number referred who fell into the 'others' category which assessors specified as including eating disorders and issues relating to sexual abuse. Of the people referred as requiring a routine appointment the largest proportion reported anxiety symptoms. People having multiple difficulties lead to referrers requesting a priority appointment. Multiple difficulties may be more distressing for the person as well as being difficult to manage using medication. People describing depressive symptoms were also more likely to receive a priority appointment, which appeared to be due to the perceived increased risk of self harm or suicide.

The level of agreement on the priority of the referral between assessors and referrers was high for routine and soon appointments, though the appropriateness of psychological intervention for the person was not assessed. Referrers and assessors however disagreed

about the majority of ‘urgent’ referrals. It is not clear in some cases if there was a change in circumstances between the referral being made and the person being assessed which lead to a different evaluation of urgency. Psychiatrists referred a similar proportion of people where the assessor disagreed with the level of urgency. In some instances the referral was clearly made as urgent for service reasons rather than because of the clients objective need, for example, an imminent case conference or because, as in one case, the referrer “forgot to send the referral in earlier”. Although understandable, this makes managing an already long waiting list, very difficult as the more priority referrals that are made, the longer people have to wait for routine appointments.

The level of agreement between the evaluation of priority appointment appropriateness from the referral letter and at assessment was high, (98% for routine referrals, 95% for ‘soon’ referrals and 85% for urgent referrals), suggesting that it would be appropriate in some cases, for the assessor to reassign the level of priority for appointments on the basis of the referral alone. There could be little gain in accuracy if everyone referred was given an assessment appointment prior to being placed on the waiting list, as suggested by Geekie (1995), given the high level of agreement between evaluation from the referral letter and at assessment.

In addition to inappropriate priority referrals, clinicians were also concerned that there may be some people who were having to wait 20 weeks for an appointment who should have been seen urgently. Unfortunately this was difficult to evaluate as four of the five referrals for whom the assessor thought a priority referral might have been more appropriate (from the referral letter), did not attend. This in itself could be significant but there is no system in place for following up people who have not attended.

The table of possible reasons for a priority referral was useful, and covered most eventualities though a number of reasons will be added. These include health issues, for example issues surrounding diagnosis of physical illness/disability and fertility/pregnancy issues; and change in circumstances e.g. leaving prison. These reasons will be incorporated into guidelines for referrers regarding what the department members feel are appropriate reasons for requesting a priority appointment. In addition to the intended benefit of referrers working with similar ideas of what a priority referral may involve, it may have the added

benefit of making it easier to evaluate priority from the referral letter if it prompts the referrer to address directly in the letter why an individual requires a priority appointment.

There are lots of questions still to be asked about priority referrals, for example are there particular people who, regardless of the severity of their difficulties, are more likely to get a priority appointment? Is there a way of addressing this so it is the need, rather than the passive or assertive nature for example, of the person (or referrer) involved that determines the speed of response?

Recommendations

1. Circulate guidelines about priority referrals to referrers.
2. Have a regular case allocation meeting which would allow:-
 - a) additional information to be sought from the referrer regarding the priority of the referral.
 - b) inappropriate referrals could be identified quickly allowing a more appropriate treatment option to be sought
 - c) referrals suitable for groups could be identified quickly.

Conclusion

There is a high level of agreement between referrers and assessors ideas of 'routine' and 'soon' referrals however there is disagreement as to who requires an urgent appointment. The recommendations highlight a number of ways of altering the system. This includes giving GPs guidelines outlining the psychologists view of urgency to encourage greater consistency across the prioritisation of appointments. The impact of the implementation of these recommendations should be audited to evaluate their effectiveness.

Looking at priority referral patterns is just one aspect of trying to provide a good service and even if it is felt that priority referrals are all appropriate, there will still be the underlying problem of long waiting lists however it is a starting point.

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Tables

Age Group	16-25			26-35			36-45			46-55			56-65			65+		
	Type of referral	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.	% of ref. type	# of ref.
Routine		13	48%		60%	27		16	64%	12	75%	3	43%	1	100%			
Soon		11	41%		22%	10		5	20%	3	19%	1	14%	0	0			
Urgent		3	11%		13%	6		2	8%	1	6%	3	43%	0	0			
Re-refer		0	0		5%	2		2	8%	0	0	0	0	0	0			
Total		27		45				25		16		7		1				

Table 1 Age categories compared with type of referral

Attendance	Attended		Cancelled		Did Not Attend (DNA)	
Type of referral	# of referrals	% of referrals	# of referrals	% of referrals	# of referrals	% of referrals
Routine	54	75%	1	1.4%	17	23.6%
Soon	21	70%	1	3.3%	8	26.6%
Urgent	13	86.6%	0	0%	2	13.3%
Re-referred	4	100%	0	0%	0	0%
Total	92	76%	2	1.6%	27	22.3%

Table 2 Attendance at appointment compared with type of referral

Presenting Problem	Number of referral	% of referrals
Depression	20	16.5%
Anxiety	29	24%
Psychotic	0	0
Addiction	1	0.8%
Relationship Problems	7	6%
Personality Related Issues	0	0
Psychometric Assessment	1	0.8%
Others	25	21%
Depression and Anxiety	12	10%
Depression and Others	6	5%
Anxiety and Addiction	2	1.6%
Anxiety and Others	8	7%
Relationship Problems and Personality Related Issues	2	1.6%
Relationship Problems and Others	4	3%
Other combinations	7	6%

Table 3. Proportion of People referred with different presenting problems.

Type of ref.	Routine		Soon		Urgent	
Presenting Problem	# of ref.	% of ref.	# of ref.	% of ref.	# of ref.	% of ref.
Depression	12	10%	6	5%	2	1.7%
Anxiety	23	19%	2	1.7%	3	2.5%
Others	15	12.4%	7	5.8%	2	1.7%
Combination	17	14%	12	10%	7	5.8%

Table 4. Presenting Problem with regard to type of referral

Type of Referral	People <u>seen</u> during a <u>2month</u> period in 1997		People <u>referred</u> during a <u>3month</u> period in 1996	
	# of ref.	% of ref.	# of ref.	% of ref.
Routine	72	60%	248	78.5%
Soon	30	25%	48	15.2%
Urgent	15	12%	20	6.3%
Re-referred	4	3%	N/A	N/A
Total	121	100%	316	100%

Table 5. Comparison between people seen in 1997 audit and people referred in 1996 audit.

Attendance at 1 st appointment	Type of ref.	Attended	Cancelled	Did not attend
1997	soon	70%	3.3%	26.6%
	urgent	86.6%	0%	13.3%
1996	soon	75%	17.2%	7.3%
	urgent	61%	16.7%	22.3%

Table 6. Comparison of attendance patterns of the people seen in 1996 and 1997.

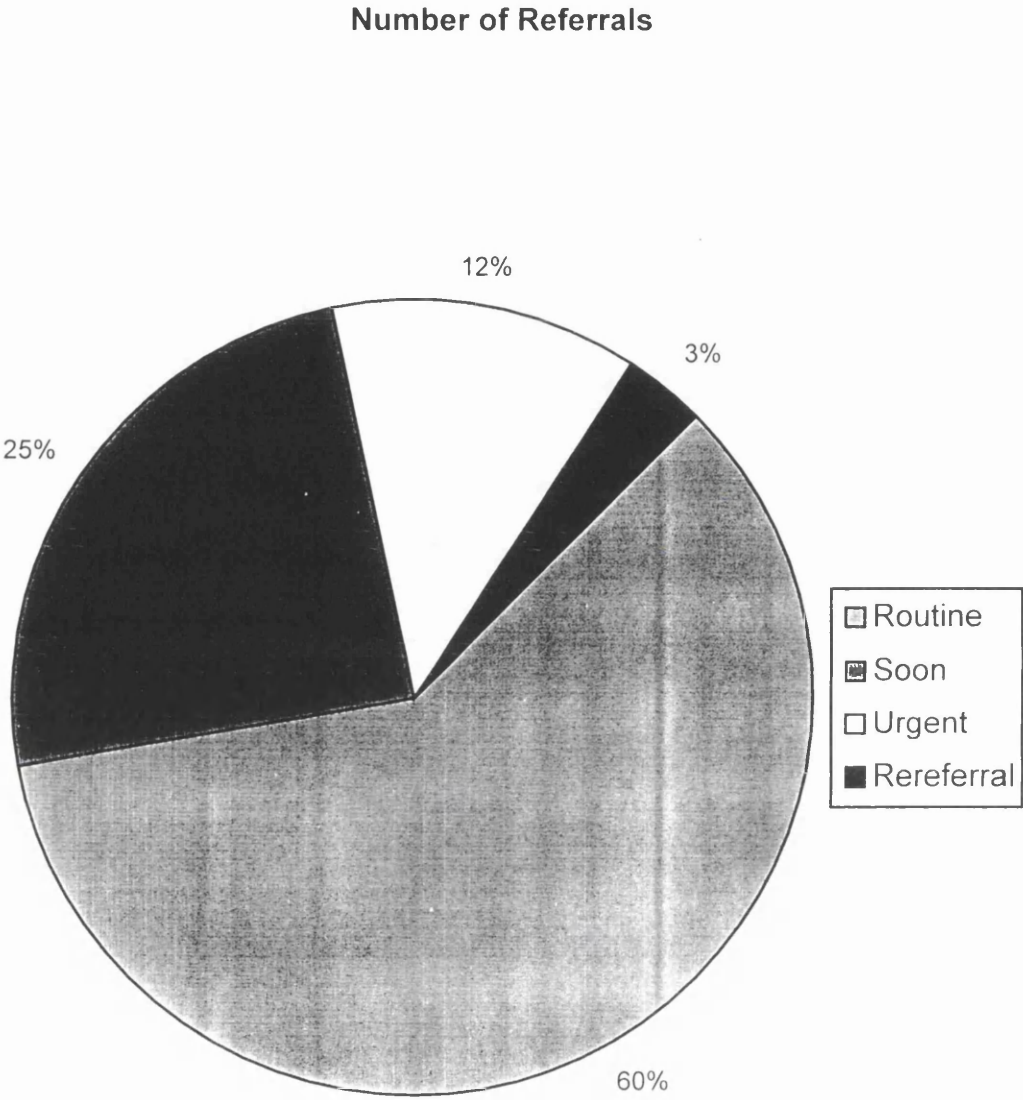


Figure 1. Pie Chart of the Proportion of ‘urgent’, ‘soon’, ‘routine’ referrals and rereferrals

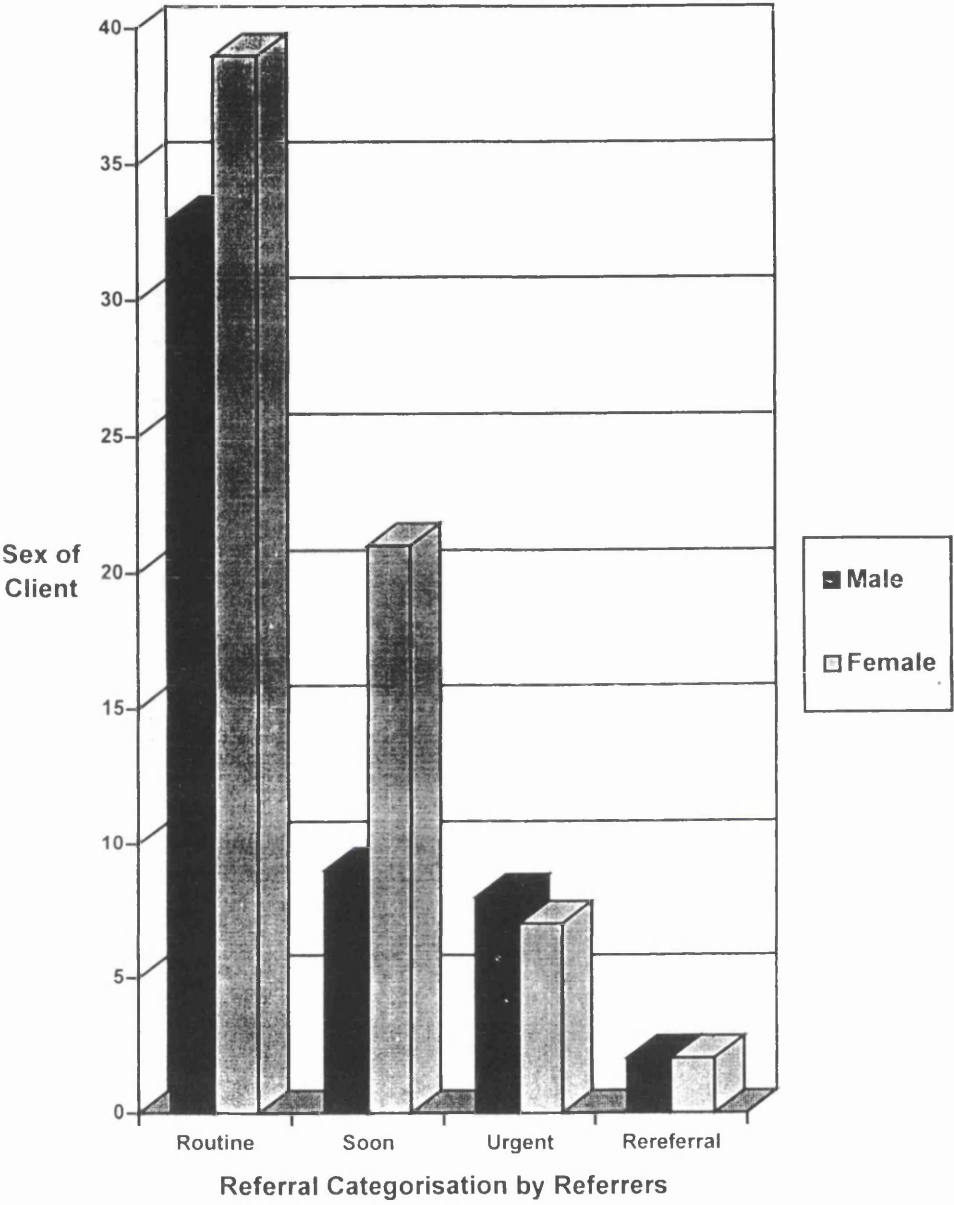


Figure 2. Bar Chart Showing the Proportion of Male and Female Priority and Routine Referrals

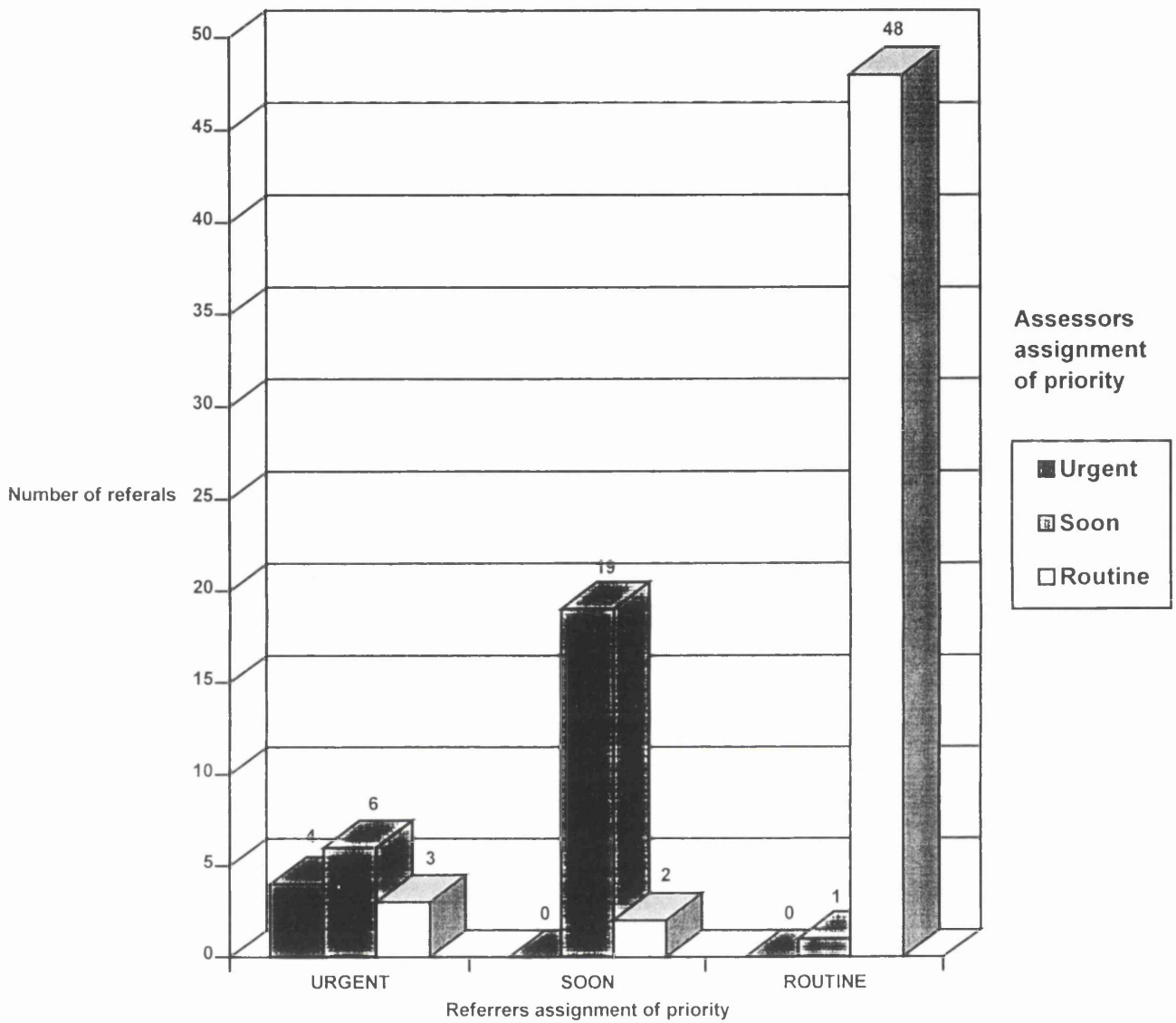


Figure 3. Bar Chart Showing the Level of Agreement between the Referrer and Assessor Prior to the Assessment

Research Case Study 1

Issues Surrounding the Diagnosis of Autism in a Deaf Man

Abstract

A case is presented of a 29 year old man who has been deaf from birth as a result of Rubella. He was referred to the Community Learning Disability Team as staff at his day centre were concerned about his level of understanding in some social situations and requested advice regarding the most appropriate strategies for facilitating his learning. The possibility of whether his difficulties with social interaction were due to Autism was raised and investigated. Literature discussing a link between Rubella and disorders in the autistic continuum was considered as well as the impact that congenital deafness has upon the development of social understanding and a Theory of Mind. This case highlights the difficulties of diagnosing Autism in a person with communication difficulties and considers ways of administering standard assessment tools to a person who communicates using sign language.

Research Case Study 2

The Role of Maternal Depression in the Development of Childhood Depression

Abstract

A case is presented of an 8 year old boy who was referred with symptoms of depression including low mood, somatic complaints and feelings of anger. On assessment it was established that his mother had a history of depressive episodes including a period of hospitalisation. In addition to this the boy had experienced a number of negative life events including his parents' separation and his grandfather's death. The role of maternal depression in a child's depressive symptoms was considered along with treatment strategies to address both the mother-child relationship and the child's own symptoms. It was found that this double focus was effective in reducing the child's reports of low mood, the mothers reports of mood and behaviour and the mother's level of stress. This was maintained at a 9 month follow up with further improvement.

Research Case Study 3

An Evaluation of Beebe's Integrative Model of Bulimia Nervosa and Depression using a Clinical Case

Abstract

A case is presented of an 18 year old woman with a history of bulimia nervosa and depression. Literature regarding the link between these two disorders is briefly reviewed and an integrative model by Beebe (1994) is presented. The utility of this model in terms of formulation, treatment choice and outcome is considered. Implications and limitations of the model are discussed. This case highlights issues regarding treatment of comorbid bulimia and depression and the role the integrative model can play in formulation and treatment.

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NOTES FOR CONTRIBUTORS

1. The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour, e.g. neuropsychology, age associated CNS changes and pharmacological (in the later case an explicit psychological analysis is also required), through studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicit social and psychological levels of analysis. The general focus of studies in an abnormal behaviour such as that described and classified by current diagnostic systems (ICD-10, DSM-IV) but it is not bound by the exclusive use of such diagnostic systems. The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

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British Journal of Clinical Psychology, 32, 460-462.

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Greater Glasgow Community and Mental Health Services NHS Trust

Information and consent form for Participants

A Study of Anxiety

My name is Jane Mindham and I work for the Health Service. I am a trainee psychologist. I am interested in the way we feel especially when we feel ‘wound up’ or ‘edgy’.

I would like people to help me by talking to me about this and looking at some pictures. It will last about an hour. I would also like to measure your heart beat which will not hurt.

It is up to you whether you would like to talk to me. If you decide not to take part it will not affect your care or treatment in any way. If you say you want to talk to me, you can still change your mind later.

I won’t tell anybody what we have discussed without your permission.

I would like to talk to Jane Mindham about how I feel.

Signed: Date:

Name:

Consent was given verbally: Yes/No

Greater Glasgow Community and Mental Health Services NHS Trust

Information for participants

My name is Jane Mindham and I am a clinical psychology trainee, employed by Greater Glasgow Community and Mental Health Services NHS Trust. As part of my postgraduate qualification, I am developing a questionnaire about anxiety for use with people with a learning disability. I would also like people without a learning disability to complete the questionnaire so I can see how useful it is compared with other anxiety questionnaires. I have therefore asked my colleagues to give this questionnaire to people they see who do not have a learning disability and sometimes feel anxious.

The questionnaires will remain anonymous, though I do need your name for this consent form. You are under no obligation to complete the questionnaire, and refusing to do so will not affect your treatment or care in any way.

I agree to take part in a study about anxiety. I am happy to fill out the relevant questionnaire.

Signature.....

Date.....

Name (printed)

Greater Glasgow Community and Mental Health Services NHS Trust

Information for the Resource Centres for People with a Learning Disability

My name is Jane Mindham and I am a clinical psychology trainee, employed by Greater Glasgow Community and Mental Health Services Trust. As part of my postgraduate qualification, I am developing a questionnaire about anxiety for use with people with a learning disability. I was wondering if you, as a team, would be agreeable to me contacting some of the people who are on your caseload who have a diagnosis of anxiety.

The study proposal has been approved by Greater Glasgow Community and Mental Health Service Trust. I am hoping to see people who attend a number of different resource centres within the Glasgow area.

There will be two focus groups of 3-4 people with a learning disability anxiety (though not necessarily people from your area) and I will be asking them about their feelings and how they express. The participants will include 17 people who have a learning disability and have been diagnosed as anxious, 17 people with a learning disability but who are not clinically anxious and 17 people who are anxious but do not have a learning disability.

The main study will involve the PAS-ADD structured interview which has been designed for use with people with a learning disability to pick up mental health problems. This will last approximately one hour. S/he will also be asked the questions from the questionnaire that is being developed.

A small number of participants will be asked to participate in a second part of the study which will take approximately one hour, on another occasion, lasting approximately one hour. This will involve the participants pulse rate being monitored throughout the session using a watch-type device called a pulse-oximeter. They will then be asked the questions from the questionnaire and will be shown pictures of a number of items including a spider and a dog. They will be asked about how this made them feel. If anyone appears upset or distressed, no further pictures will be shown and efforts will be made to calm the person down. The participant will be free to leave at any time.

If you agree to suggest names of people with a diagnosis of anxiety who may be suitable for the study, I will then ask those people if they would like to take part in the study. It will be made clear to them that they are under no obligation to take part and they can drop-out at any point.

All information will be confidential but in the eventuality that someone becomes upset, this will be discussed with the centre staff and carers will be contacted.

If you are happy for me to contact people attending your resource centre and see people within the centre please sign the section below and return the form to me in the stamp addressed envelope provided. I have enclosed a second copy of the form for your own records and copies of the information which will be given to potential participants.

I give my consent for Jane Mindham (Trainee Clinical Psychologist) to contact people who attendResource Centre to see if they would be interested in participating in a study into anxiety as described above.

Signed..... Name (printed).....

Position Date

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If authors wish to have their work peer reviewed anonymously, they must submit their work without personal identification; names and addresses of all authors should be given in the covering letter. Otherwise, the names of the authors should appear on the title page in the form that is wished for publication, and the names, degrees, affiliations and full addresses at the time the work described in the paper was carried out given at the end of the paper.

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A structured summary should be given at the beginning of the article, incorporating the following headings: Background; Aims; Method; Results; Conclusions; Declaration of interest. The latter should list fees and grants from, employment by, consultancy for, shared ownership in, or any close relationship with, an organisation whose interests, financial or otherwise, may be affected by the publication of your paper. This pertains to all the authors of the study. The summary should be no more than 150 words. Editorials do not require summaries.

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Personal communications need written authorisation; they should not be included in the reference list. No other citation of unpublished work, including unpublished conference presentations, is permissible.

TABLES

Each table should be submitted on a separate sheet. They should be numbered and have an appropriate heading. The tables should be mentioned in the text but must not duplicate information in the text. The heading of the table, together with any footnotes or comments, should be self-explanatory. The desired position of the table in the manuscript should be indicated. Do not tabulate lists, which should be incorporated into the text, where, if necessary, they may be displayed.

Authors must obtain permission if they intend to use tables from other sources, and due acknowledgement should be made in a footnote to the table.

FIGURES

Figures should be individual glossy photographs, or other camera-ready prints, or good-quality output from a computer, not photocopies, clearly numbered and captioned below. Avoid cluttering figures with explanatory text, which is better incorporated succinctly in the legend. Lettering should be parallel to the axes. Units must be clearly indicated and should be presented in the form quantity:unit (note: 'litre' should be spelled out in full unless modified to ml, dl, etc.).

Authors must obtain permission if they intend to use figures from other sources, and due acknowledgement should be made in the legend.

Colour figures may be reproduced if authors are able to cover the costs.

STATISTICS

Not all papers require statistical analysis. Case histories and studies with very small numbers are examples. In larger studies where statistical analyses are included it is necessary to describe these in language that is comprehensible to the non-psychiatrist as well as the medical statistician. Particular attention should be paid to clear description of study designs and objectives, and evidence that the statistical procedures used were both appropriate for the hypotheses tested and correctly interpreted. The statistical analyses should be planned before data are collected and full explanations given for any *post-hoc* analyses carried out. The value of test statistics used (e.g. χ^2 , t , F -ratio) should be given as well as their significance levels

so that their derivation can be understood. Standard deviations and errors should not be reported as \pm , but should be specified and referred to in parentheses.

Trends should not be reported unless they have been supported by appropriate statistical analyses for trends.

The use of percentages to report results from small samples is discouraged, other than where this facilitates comparisons. The number of decimal places to which numbers are given should reflect the accuracy of the determination, and estimates of error should be given for statistics.

A brief and useful introduction to the place of confidence intervals is given by Gardner & Altman (1990, *British Journal of Psychiatry*, 156, 472-474). Use of these is encouraged but not mandatory.

Authors are encouraged to include estimates of statistical power where appropriate. To report a difference as being statistically significant is generally insufficient, and comment should be made about the magnitude and direction of change.

GENERAL

All abbreviations must be spelt out on first usage.

The generic names of drugs should be used, and the source of any compounds not yet available on general prescription should be indicated.

Generally, SI units should be used; where they are not, the SI equivalent should be included in parentheses. Units should not use indices: i.e. report g/ml, not g ml^{-1} .

The use of notes separate to the text should generally be avoided, whether they

be footnotes or a separate section at the end of a paper. A footnote to the first page may, however, be included to give some general information concerning the paper.

If an individual patient is described, his or her consent should be obtained and submitted with the manuscript. The patient should read the report before submission. Where the patient is not able to give informed consent, it should be obtained from an authorised person. Where the patient refuses to give consent, the case study can only be written up if personal details and dates and other information which identifies the patient is omitted to ensure that there is no breach of confidentiality. Contributors should be aware of the risk of complaint by patients in respect of defamation and breach of confidentiality, and where concerned should seek advice.

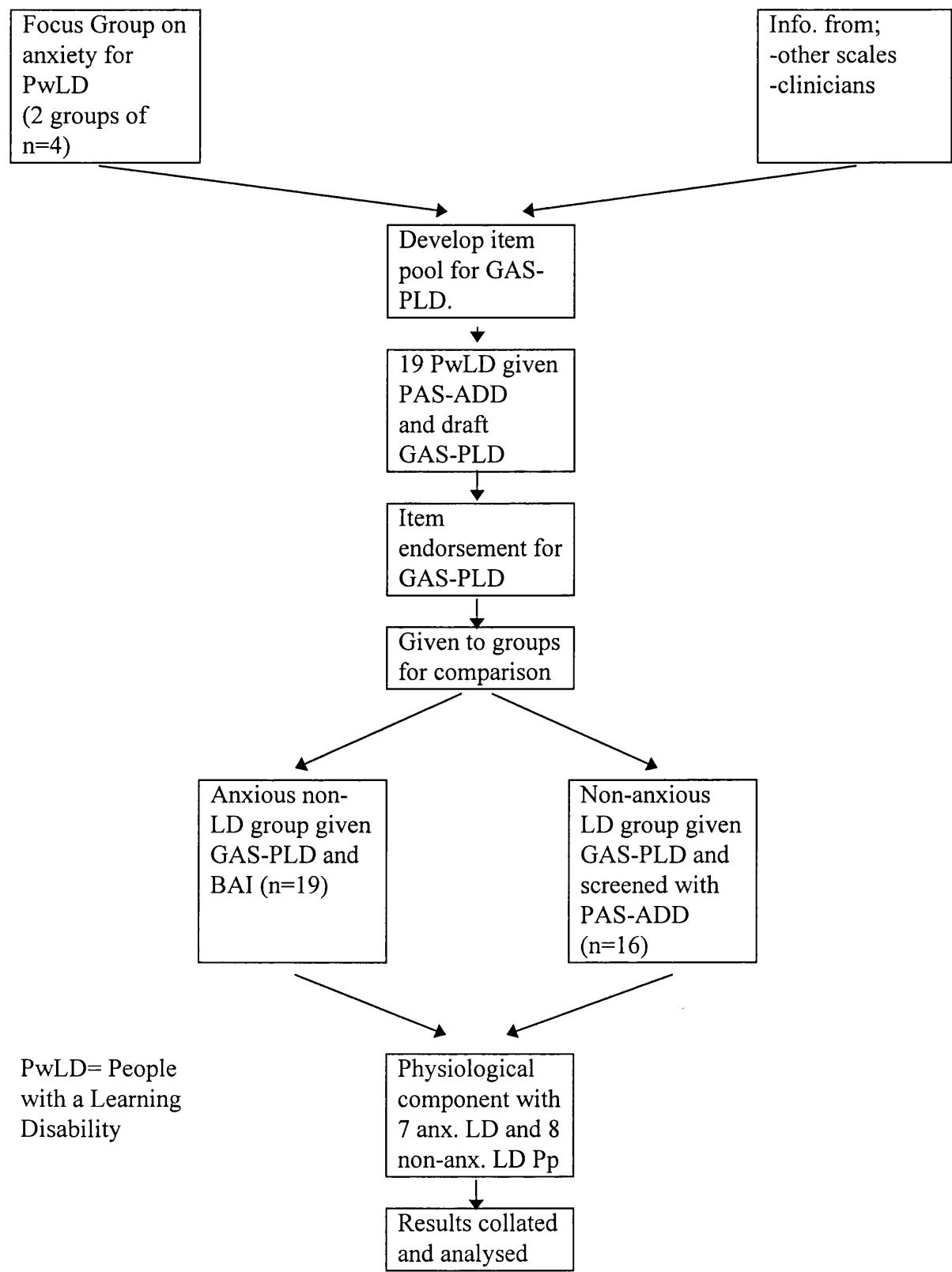
PROOFS

A proof will be sent to the corresponding author of an article. Offprints, which are prepared at the same time as the *BJP*, should be ordered when the proof is returned to the Editor. Offprints are despatched up to six weeks after publication. The form assigning copyright to the College must be returned with the proof.

LETTERS TO THE EDITOR

Letters must be double spaced and should not exceed 350 words. They will be edited for clarity and conformity with *BJP* style and may be shortened. There should be no more than five references. Proofs will not be sent to authors.

Figure 1. Flow chart of the experimental design



Draft GAS-LD

Hello. My name is What is your name?.....
What do you like doing?.....
What have you been doing recently?.....
(Ask number of questions to identify an event approximately a week ago as an anchor event.
If necessary ask a carer prior to the interview.)
Anchor event.....

I am going to ask you some questions about how you have been feeling since *anchor event/over the last week*. There is not a right or wrong answer, it is just about how you feel.
If I have not explained something clearly, please ask me to tell you what I mean.

For each question, I will ask you if you have never felt like this, if you sometimes feel like this or if you feel like this all the time. *Show cue card with visual representation of never, sometimes and always. Check that participant understands by administering following questions:-*

- Have you always lived in *area s/he lives in?* Yes /No
- Do you sometimes go to the cinema? Yes/No
- It never rains here. Yes/No
- Gives same response to each question* Yes/No
- Give response options and show cue card after each question.*

Section A - Worries

	Never	Sometimes	Always
	0	1	2
What kinds of things make you uptight/worry?.....			
.....			
* x 1. Do you worry a lot? (<i>Do you feel worked up/ wound up/ uptight ? Do you feel 'up to high doh'? Or any other language or colloquialisms that seems appropriate</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* 2. Do you have lots of thoughts that go round in your head? (<i>Thoughts that you can not stop or that seem to come from nowhere?)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x 3. Do you worry about your parents/family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ x 4. Do you worry about what will happen in the future? (<i>Tailor the question to suit the individual e.g. Do you worry about what will happen if you can't live with your Mum anymore?</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* 5. Do you worry that something awful might happen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* 6. Do you worry if you do not feel well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ x 7. Is there anything you do every week? Do you worry if you can not do it? (<i>i.e. going to chapel /church, going to the club</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x 8. Do you worry if you are doing something new?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* 9. Do you worry about what you are doing tomorrow?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
□ x 10. Do you worry about getting hurt? (<i>being injured either through an accident or being assaulted - physically or sexually</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x 11. Can you stop worrying? (Reverse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* x 12. Do you worry about death/dying?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section A Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>

Section B - Specific Fears

	Never	Sometimes	Always
	0	1	2
Have you felt scared of anything since			
13. Do you get scared in the dark? <i>Think of being in bed with all the lights out. It is very dark. Do you find this frightening?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you feel scared if you are high up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you feel scared in lifts or escalators? <i>Would you go in/on a lift/escalator?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Are you scared of dogs? <i>Would you stroke/clap a dog?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Are you scared of spiders? <i>Would you go near a spider?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you feel scared going to see the doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you feel scared going to see the dentist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Do you feel scared going to see the social worker?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Do you feel scared meeting new people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Do you feel scared speaking on the phone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Do you feel scared in busy place?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Do you feel scared if you can not see the way out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Do you feel scared in wide open spaces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section B Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>

Section C - Physiological Symptoms

26. Do you ever feel very hot and sweaty ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Does your heart beat faster?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Do your hands and legs shake?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Do you ever feel dizzy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Does your stomach ever feel funny, like butterflies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Do you ever feel breathless? <i>(Do you ever find it hard to breathe? Do you ever think you can not breathe?)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Do your hands or face feel tingly, like pins and needles?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Do you feel like you need to go to the toilet more than usual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Is it difficult to sit still?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Do you feel panicky?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section C Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>
Anxiety Score A =	<input type="text"/>		
Anxiety Score B =	<input type="text"/>		
Anxiety Score C =	<input type="text"/>		
Total Anxiety Score =	<input type="text"/>		

Concluding comments

Thank you for chatting to me.
What did you think about all those questions?
What are you doing later today?

Participants response

- | | | | |
|---|--------------------------|--------------------------|--------------------------|
| • Did s/he concentrate well? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Did s/he appear to understand the questions? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Did s/he mind being asked the questions? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Did s/he appear anxious during the assessment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Did s/he always give the same response or agree with you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Source of Items

- × Focus Group
- Questionnaires
- Clinicians
- Wording changes from clinicians

GAS-LD

Hello. My name is What is your name?.....
What do you like doing?.....
What have you been doing recently?.....
(Ask number of questions to identify an event approximately a week ago as an anchor event.
If necessary ask a carer prior to the interview.)
Anchor event.....

I am going to ask you some questions about how you have been feeling since *anchor event/over the last week*.
There is not a right or wrong answer, it is just about how you feel.
If I have not explained something clearly, please ask me to tell you what I mean.

For each question, I will ask you if you have never felt like this, if you sometimes feel like this or if you feel like this all the time. *Show cue card with visual representation of never, sometimes and always. Check that participant understands by administering following questions:-*

Have you always lived in <i>area s/he lives in?</i>	Yes /No
Do you sometimes go to the cinema?	Yes/No
It never rains here.	Yes/No
<i>Gives same response to each question</i>	<i>Yes/No</i>

Give response options and show cue card after each question.

Section A - Worries	Never Sometimes Always		
	0	1	2
What kinds of things make you uptight/worry?.....			
1. Do you worry a lot? (<i>Do you feel worked up/ wound up/ uptight ? Do you feel 'up to high doh'? Or any other language or colloquialisms that seems appropriate</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you have lots of thoughts that go round in your head? (<i>Thoughts that you can not stop or that seem to come from nowhere?)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you worry about your parents/family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you worry about what will happen in the future? (<i>Tailor the question to suit the individual e.g. Do you worry about what will happen if you can't live with your Mum anymore?</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you worry that something awful might happen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you worry if you do not feel well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you worry if you are doing something new?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you worry about what you are doing tomorrow?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Can you stop worrying? (Reverse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you worry about death/dying?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section A Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>

Section B - Specific Fears

	Never	Sometimes	Always
	0	1	2
Have you felt scared of anything since			
11. Do you get scared in the dark? <i>Think of being in bed with all the lights out. It is very dark.</i> <i>Do you find this frightening?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you feel scared if you are high up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you feel scared in lifts or escalators? <i>Would you go in/on a lift/escalator?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Are you scared of dogs? <i>Would you stroke/clap a dog?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Are you scared of spiders? <i>Would you go near a spider?</i> Yes/No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you feel scared going to see the doctor or dentist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you feel scared meeting new people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you feel scared in busy place?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you feel scared in wide open spaces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section B Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>

Section C - Physiological Symptoms

20. Do you ever feel very hot and sweaty?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Does your heart beat faster?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Do your hands and legs shake?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Does your stomach ever feel funny, like butterflies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Do you ever feel breathless? <i>(Do you ever find it hard to breathe? Do you ever think you can not breathe?)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Do you feel like you need to go to the toilet more than usual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Is it difficult to sit still?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Do you feel panicky?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section C Total =	<input type="text"/>	<input type="text"/>	<input type="text"/>

Score 0 for never, 1 for sometimes and 2 for always

Anxiety Score A =	<input type="text"/>
Anxiety Score B =	<input type="text"/>
Anxiety Score C =	<input type="text"/>
Total Anxiety Score =	<input type="text"/>

Concluding comments

Thank you for chatting to me.
What did you think about all those questions?
What are you doing later today?

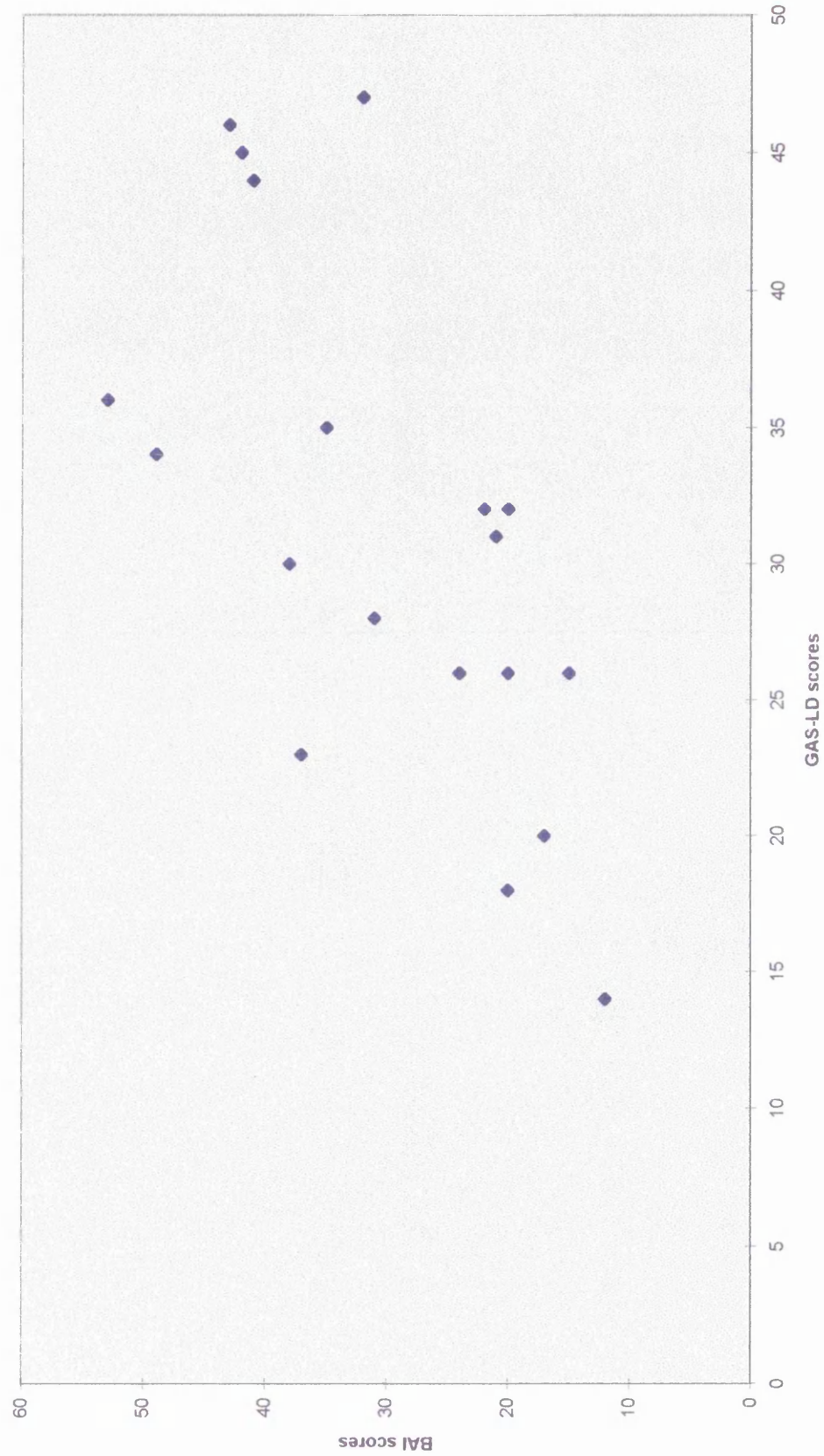
Participants response

• Did s/he concentrate well?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Did s/he appear to understand the questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Did s/he mind being asked the questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Did s/he appear anxious during the assessment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Did s/he always give the same response or agree with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Items Removed from Draft GAS-LD and reasons for their removal

Items	Reason for removal
7. Is there anything you do every week? Do you worry if you can not do it? (<i>i.e. going to chapel /church, going to the club</i>)	Misunderstood by participants
10. Do you worry about getting hurt? (<i>being injured either through an accident or being assaulted - physically or sexually</i>)	Only endorsed by 6 people, less than 40%
18. Do you feel scared going to see the doctor? 19. Do you feel scared going to see the dentist?	The items were combined to form one question.
20. Do you feel scared going to see the social worker?	Only endorsed by 2 people, less than 40%
22. Do you feel scared speaking on the phone?	Only endorsed by 4 people, less than 40%
24. Do you feel scared if you can not see the way out?	Only endorsed by 4 people, less than 40%
29. Do you ever feel dizzy?	Misunderstood by participants.
32. Do your hands or face feel tingly, like pins and needles?	Only endorsed by 9 people, less than 75%

Scatter Plot of Scores on GAS-LD and BAI















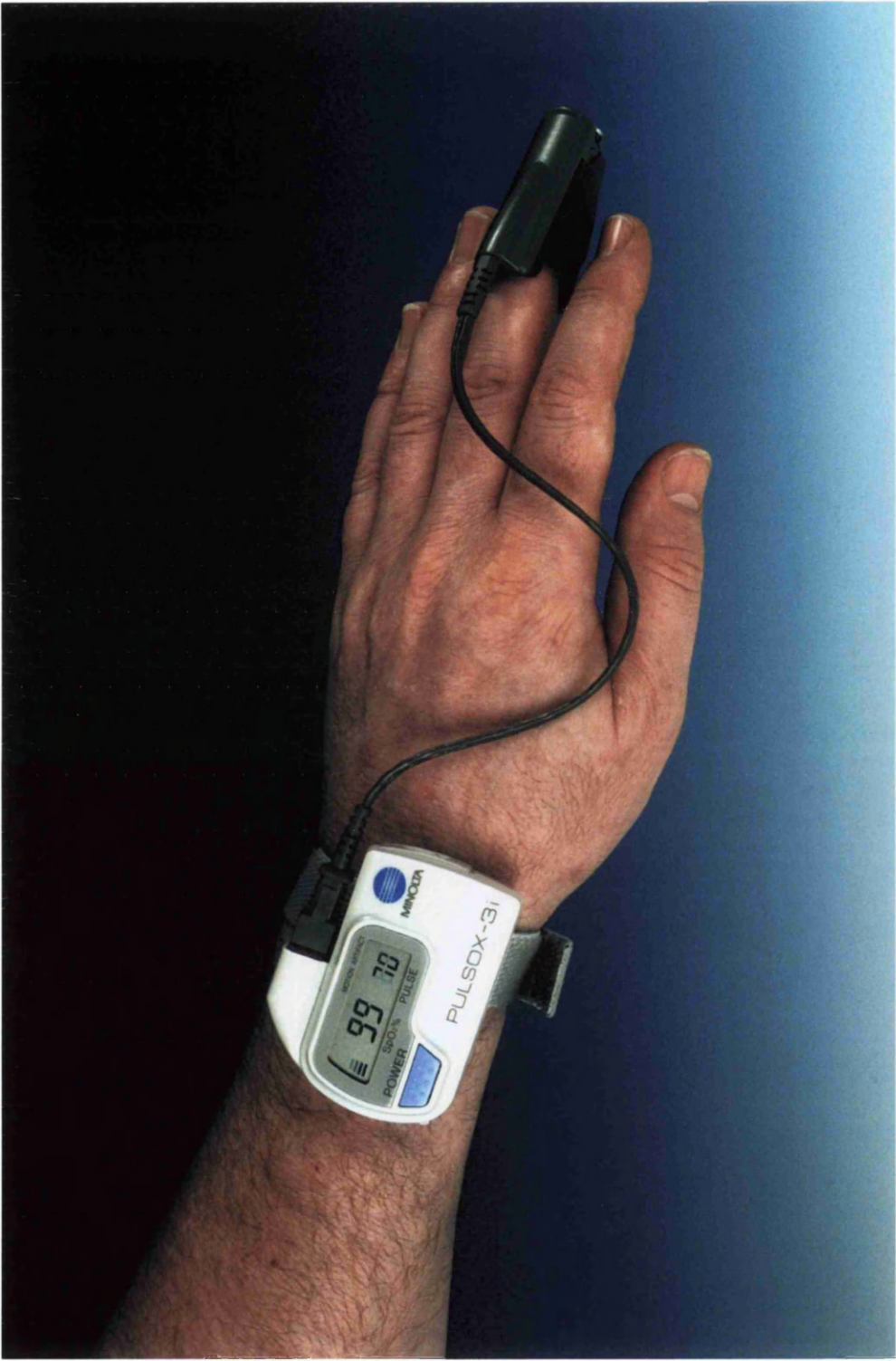


Table 2. Matrix of the Principal Components Analysis (PCA)

Question	Component					
	1	2	3	4	5	6
1	.804	-.240	-.279	<.01	<.01	<.01
2	.809	-.223	-.235	-.178	<.01	<.01
3	.677	.122	-.277	-.267	.323	<.01
4	.716	.336	-.205	<.01	<.01	<.01
5	.835	.126	-.135	<.01	<.01	<.01
6	.747	-.115	-.108	<.01	.297	.164
7	.670	.252	-.312	-.179	<.01	.344
8	.578	.499	-.355	.119	.116	-.158
9	.751	-.279	-.148	<.01	<.01	<.01
10	.701	.182	<.01	<.01	<.01	-.290
11	.540	.430	.241	.102	.211	-.250
12	.487	<.01	.397	-.548	.166	<.01
13	.419	<.01	.392	-.119	.570	<.01
14	.476	<.01	<.01	.625	.286	.102
15	.321	.430	.210	.280	-.230	.370
16	.544	.232	.395	-.132	-.357	<.01
17	.668	.403	-.101	-.141	-.309	.195
18	.738	.200	<.01	<.01	<.01	<.01
19	.536	.107	.546	.303	.151	.220

20	.659	-.289	<.01	.273	-.232	-.196
21	.702	-.476	.113	<.01	-.101	<.01
22	.821	-.277	<.01	.201	-.152	<.01
23	.640	-.539	.123	<.01	-.103	.347
24	.757	-.351	<.01	.123	<.01	<.01
25	.461	<.01	.339	.103	<.01	-.471
26	.721	<.01	.109	-.266	-.308	-.194
27	.899	<.01	<.01	<.01	-.132	<.01

Notes for Contributors

Journal of Mental Health welcomes original communications and articles which have relevance to the field of mental health. Papers are accepted on the understanding that they are subject to editorial revision and that their contents have not been published elsewhere.

Manuscripts should be sent to the Executive Editor, Professor Ray J. Hodgson, Centre for Applied Public Health Medicine, Lansdowne Hospital, University of Wales College of Medicine, Cardiff CF1 8UL, United Kingdom.

To expedite assessment, 3 complete copies of each manuscript should be submitted. All submissions should be in the style of the American Psychological Association (*Publication Manual*, Fourth edition, 1994). Papers should be typed on one side of the paper, double spaced (including the references), with margins of at least 2.5 cm (1 inch). The first sheet should include the full title of the paper, a short title not exceeding 45 characters (for a running title at the head of each page), names of authors and the address where the work was carried out. All pages must be numbered. Significant delays may occur to manuscripts that do not conform to journal style. Each article should be accompanied by an abstract of not more than 150 words. Manuscripts should not exceed 6000 words in total, unless previously agreed by the Editor. The full postal address of the author who will check proofs and receive correspondence and offprints should also be included. Footnotes should be avoided where possible.

In order to improve accuracy and expedite publication, authors are requested to submit the *final* and *revised* version of their manuscript on disk. The disk should contain the paper saved in its original application software (e.g. WordPerfect or Microsoft Word), and as either Word for Macintosh, rich text format (RTF) if available, or as a text or ASCII (plain) text file. The disk should be clearly labelled with the author(s) name, paper title, file names and the software used. A good quality copy of the manuscript is *always* required.

References should follow the style of the American Psychological Association. All publications cited in the text should be listed following the text; similarly, all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Folkman, 1992) or (Sartory & Stern, 1979), or if there are more than two authors (Gallico *et al.*, 1985). Where several references are quoted consecutively, or within a single year, within the text the order should be alphabetical, e.g. (Mawson, 1992; Parry & Watts, 1989) and (Grey, 1992; Kelly, 1992; Smith, 1992). If more than one paper from the same author(s) and year are listed, the date should be followed by (a), (b), etc., e.g. (Cobb, 1992a).

References should be listed alphabetically by author on a separate sheet(s) (double spaced) in the following standard form, capitalisation and punctuation:

- a) For periodical articles (titles of journals should *not* be abbreviated):
Rachman, S., Cobb, J., Grey, S.J., McDonald, B., Mawson, D., Sartory, G. & Stern, R. (1979). The behavioural treatment of obsessive-compulsive disorders, with and without clomipramine. *Behaviour Research and Therapy*, 17, 467-478.
- b) For books:
Powell, T.J. & Enright, S.J. (1990). *Anxiety and Stress Management*. London: Routledge.
- c) For chapters within multi-authored books:
Hodgson, R.J. & Rollnick, S. (1989). More fun, less stress: How to survive in research. In G. Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75-89). London: Lawrence Erlbaum.

Journal titles should not be abbreviated and unnecessary references should be avoided.

Clear, grammatical and tabular presentation is strongly encouraged.

Illustrations should not be inserted in the text. Each should be provided separately, and numbered on the back with the figure number, title of the paper, and names of the author(s). Three copies of all figures must be submitted. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Fig 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate sheet and should make interpretation possible without reference to the text. Captions should include keys to symbols. Where possible it would help to ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

Tables should be typed on separate sheets and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should *not* be used.

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Small Scale Research Project Proposal

Priority Referrals - A Service Issue

Priority Referral Questionnaire

(please circle as appropriate)

Psychologist CC CL CM SN MV

Patient Details

Initials

Sex Male/Female

Age	16-25	26-35	36-45	46-55	56-65
-----	-------	-------	-------	-------	-------

Sector

Site of contact	Dykebar	RAH	Health Centre
-----------------	---------	-----	---------------

Referral Details

Type of referral (as indicated by GP)	Urgent	Soon	Routine	Re-referred as Priority
--	--------	------	---------	----------------------------

Source of referral	GP	Psychiatrist	Other
--------------------	----	--------------	-------

Referrer

Waiting time(weeks)

Attendance at 1st appointment	Attended	Cancelled	DNA
-------------------------------	----------	-----------	-----

Presenting Problem	Depression Anxiety Psychotic Addiction Relationship Problems Personality Related Issues Psychometric Assessment Others
--------------------	---

Please complete before seeing person for assessment

Rate degree of appropriateness of referral based on referral letter (please mark as appropriate)

Urgent 0 | 100

Soon 0 | 100

Routine 0	100
-----------	-----

Should have been:-

Reason for priority referral as indicated in referral letter (tick one or more)

Acute Crisis/Distress	
Imminent threat to job, relationship, person etc.	
Recent loss	
Recent hospitalisation	
Risk of harm to self or others	
Other (please elaborate below)	
Not clear	

Small Scale Research Project Proposal
Priority Referrals - A Service Issue

Please complete following assessment.

Rate degree of appropriateness of referral based on assessment (please mark as appropriate)

Urgent	0	_____	100
Soon	0	_____	100
Routine	0	_____	100

Should have been:- _____

Reason for referral as ascertained from the assessment (tick one or more)?

Acute Crisis/Distress	
Imminent threat to job, relationship, person etc.	
Recent loss	
Recent hospitalisation	
Risk of harm to self or others	
Other (please elaborate below)	
Not clear	

Comments:-

